



DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology : Main Research Portfolio

1) Do sex offenders experience intrusive sexual thoughts? A structured, narrative review of the phenomenology of intrusive sexual thoughts in the general, clinical and forensic population; 2) Identifying and addressing the needs of relatives in Critical Care Services at the Royal United Hospital, Bath.; 3) How do caregivers of children with co-morbid deafness and mental health difficulties experience and cope with their child's conditions?

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Research Portfolio submitted in part fulfilment of the
requirements for the Degree of Doctorate in Clinical Psychology

Doctorate in Clinical Psychology

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May 2016

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Abstracts

Literature Review:

Do sex offenders experience intrusive sexual thoughts? A structured, narrative review of the phenomenology of intrusive sexual thoughts in the general, clinical and forensic population.

The current paper explores the phenomenology of intrusive sexual thoughts in sex offenders and people with OCD. Whilst much is written about intrusive sexual thoughts in the general and clinical populations, little is known about the relevance of these cognitive phenomena in forensic settings. Currently, knowledge of intrusive sexual thoughts has become polarised within the academic literature between those with obsessive compulsive disorder, who theoretically present little risk, and sexual offenders who by definition pose significant risk. The current review aims to synthesise these territories of thought in an attempt to address the clinical and moral dilemma faced by clinicians managing intrusive sexual thoughts in an ambiguous diagnostic context. Findings from the review indicate that there are both similarities and differences in the theoretical understanding, and phenomenology in terms of thought processes, content and appraisals of sexual thoughts in these populations. Methodological and definitional inconsistencies were noted as having a detrimental impact on the development of meaningful comparative research in this field. A framework for understanding intrusive sexual thoughts in sex offenders is proposed and its implications for clinical assessment considered with a view to allowing clinicians to consider these issues in terms of treatment and risk.

Service Improvement Project:

Identifying and addressing the needs of relatives in Critical Care Services at the Royal United Hospital, Bath.

The aim of this project was to identify the needs of relatives in the Intensive Therapy Unit of the Royal United Hospital (RUH) in Bath. Existing evidence suggests that having a relative admitted to critical care can be stressful. In addition, relatives are often asked to take a more active role in the care given to inpatients during their stay. Therefore, it is increasingly important to recognise and meet the needs of relatives in the ITU department. Twenty-four relatives who accessed the ITU department of the RUH completed a questionnaire to help

identify their needs and evaluate how well these needs were being addressed by the service. Findings indicated that to be given assurances about patient care was considered the most important for relatives, followed by clear, understandable information sharing. Identified needs are discussed in terms of potential areas of improvement for the service. Recommendations for how to implement suggested improvements are discussed.

Main Research Project 1:

How do caregivers of children with co-morbid deafness and mental health difficulties experience and cope with their child's conditions?

Existing research indicates that caring for a child with additional difficulties can be challenging and stressful for caregivers (Mendenhall and Mount, 2011). Mental health problems and deafness can both be considered additional difficulties. However less is known about the impact of this co-morbid presentation in children on their caregivers. The present study explored how caregivers of children with co-morbid deafness and mental health difficulties experienced and coped with their child's conditions. The project took place in two stages. The first stage was designed to measure stress, coping and adjustment in caregivers of deaf and non-deaf children with mental health difficulties. The second stage provided some contextual background to caregiver's experiences of rearing a child with co-morbid deafness and mental health difficulties.

Main Research Project 2:

Seeking help for OCD – A community focusing study

Background. Despite the potentially severe psychosocial impact of OCD and the its treatability, evidence suggests that people wait many years to seek treatment (Stobie, Taylor, Quigley, Ewing, and Salkovskis, 2007). The psychological processes involved in the decision to seek treatment for OCD have received surprisingly little research attention. It has been documented that a lack of information can act as a barrier to seeking treatment for OCD (Robinson, Rose and Salkovskis, in press). Research in other areas has indicated that decision making outcomes correspond with areas in which people are encouraged to focus

on at the time of decision making (Wroe and Salkovskis, 2000; Wroe, Salkovskis and Rimes, 2000; Salkovskis, Rimes, Bolton and Wroe, 2010).

Objectives. The present study aimed to explore whether the type of information presented and focussed on by community controls (without OCD) influenced the likelihood that they would seek treatment if they developed OCD.

Design. An analogue study was conducted using people who were not suffering from OCD that were recruited in the community.

Methods. The seventy-five included participants were recruited through community settings to complete a focussing intervention. Participants were asked to rate how likely they would be to seek help for OCD before and after reading and rating for self-applicability, specific information designed to focus their attention either on previously identified “enabler” factors or on general information about OCD.

Results. Results indicated a significant shift in the likelihood of seeking treatment for OCD when participants were asked to focus on enabling information as opposed to more general information on OCD.

Conclusions. Providing people with any type of information about OCD is helpful in increasing the likelihood of hypothetically seeking help, however focussing on enabling factors is more facilitative in terms of adjusting people’s attitudes towards treatment seeking.

Word Counts

Critical review of the literature:	7642
Service improvement project:	4209
Main research project 1:	3811
Connecting narrative between two research projects	1135
Main research project 2:	5226
Executive Summary	812
Connecting narrative:	974

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Critical Review of the Literature

Title: Do sex offenders experience intrusive sexual thoughts?
A structured, narrative review of the phenomenology of intrusive sexual thoughts in the general, clinical and forensic population.

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Abstract

The current paper explores the phenomenology of intrusive sexual thoughts in sex offenders and people with OCD. Whilst much is written about intrusive sexual thoughts in the general and clinical populations, little is known about the relevance of these cognitive phenomena in forensic settings. Currently, knowledge of intrusive sexual thoughts has become polarised within the academic literature between those with obsessive compulsive disorder, who theoretically present little risk, and sexual offenders who by definition pose significant risk. The current review aims to synthesise these territories of thought in an attempt to address the clinical and moral dilemma faced by clinicians managing intrusive sexual thoughts in an ambiguous diagnostic context. Findings from the review indicate that there are both similarities and differences in the theoretical understanding, and phenomenology in terms of thought processes, content and appraisals of sexual thoughts in these populations. Methodological and definitional inconsistencies were noted as having a detrimental impact on the development of meaningful comparative research in this field. A framework for understanding intrusive sexual thoughts in sex offenders is proposed and its implications for clinical assessment considered with a view to allowing clinicians to consider these issues in terms of treatment and risk.

Introduction: Intrusive Thoughts, Definitions and Characteristics

Intrusive thoughts were first defined in the context of the overlap between Obsessive Compulsive Disorder and non-clinical experience (OCD). Rachman and DeSilva (1978) outlined intrusive thoughts as unwanted, repetitive thoughts, images or impulses that are appraised as unacceptable and uncontrollable by the individual. It is the negative evaluation and subsequent distress caused by these intrusions that has been the main focus of clinical research (Clark and Purdon, 1995). Intrusive thoughts are considered distinctly different to other cognitive processes and form a functional component of many psychological disorders (Salkovskis, 1985; Clark and Rhyno, 2005). Whilst intrusive thoughts can encompass a variety of content, the most common reported themes include sexual obsessions, religion, contamination, harming, symmetry and doubting (Steketee and Barlow, 2002; Clark and Rhyno, 2005). Existing research suggests that the vast majority of people experience unwanted, sudden, and involuntary thoughts (Rachman and de Silva 1978; Salkovskis and Harrison 1984; Purdon and Clark, 1993; Byers, Purdon and Clark, 1998). Experiencing these thoughts is therefore not uncommon and considered a natural process within our stream of consciousness (Clark and Purdon, 1995).

Intrusive Sexual Thoughts

Intrusive sexual thoughts are those that focus exclusively upon sexual themes, images or urges (Marshall and Langton, 2005). They can be associated with sexual arousal or anxiety, and may be accompanied by feelings of guilt or embarrassment (Cado and Leitenberg, 1990; Leitenberg and Henning, 1995; Marshall and Langton, 2005). Operational definitions of intrusive sexual thoughts are inconsistent, with terms such as sexual cognitions, obsessions, preoccupations and intrusive thoughts used interchangeably in the literature (Byers, Purdon and Clark, 1998). It is therefore possible that variations in definitions used may mean that sexual intrusions are more complicated than previously thought, which may have prevented direct comparisons across the literature.

One specific area where this discrepancy is important is the consideration of individuals' subjective appraisals of the thought as positive or negative. Evidence suggests that previous research has failed to distinguish between sexual cognitions experienced as positive, pleasant, and enjoyable as opposed to unwanted intrusive sexual thoughts (Byers *et al.*, 1998). These two concepts have been polarised in the literature. Positive sexual cognitions, labelled as fantasies, are believed to be purposely, internally derived as opposed to the unwanted, unacceptable nature of intrusive thoughts. Historically researchers in the field of sexuality have failed to differentiate between positively and negatively experienced sexual cognitions, meaning that both types of thought have been captured in the literature (Renauld and Byers; 1999). It is important to be able to distinguish between these two concepts, which could be transient and contextually driven (Byers *et al.*, 1998). This means that in one circumstance a sexual cognition could be interpreted as a fantasy whilst under different conditions, one might experience it as an unwanted and intrusive thought (Byers *et al.*, 1998). The boundary between these two concepts may therefore be less distinct than previously documented (Clark, Purdon and Byers, 2000). This was supported by, Veale *et al.* (2009) who stressed the importance of being able to make clinical distinctions when treating individuals with intrusive thoughts.

Existing evidence suggests that thoughts of a sexual content are more likely than other types of thought to be miss-diagnosed by clinicians (Glazier *et al.* 2013). Veale and colleagues (2009) in their paper about risk assessment and management of intrusive thoughts in OCD, highlighted the detrimental impact that this misclassification can have on sufferers. The authors noted that wrongly adopting overly cautious reactions to such thoughts risks further alienating sufferers, increasing their doubts and fears and subsequently increasing their

distress. Whilst Veale and colleagues (2009) do not focus solely on intrusive sexual thoughts, they make some useful contributions to the literature around phenomenology of these thoughts. In particular, consideration is given to the potential differences in thoughts of an OCD sufferer and a sex offender. The authors recommend that a sound understanding of phenomenology of intrusive thoughts is needed to make an appropriate differential diagnosis. In order to truly understand the phenomenological distinctions of something, we must consider both the differences and similarities it presents as well as any areas of uncertainty. The current paper therefore seeks to expand the foundations of this dilemma set down by Veale and colleagues (2009) in order to provide a greater understanding of the phenomenology of intrusive sexual thoughts. According to Marshall and Langton (2005) further research is needed to explore the phenomenology of intrusive sexual thoughts in sex offenders. This review aims to contribute to this gap in the literature by synthesising existing knowledge from forensic and clinical populations. The primary aim is therefore to investigate the similarities and differences in the phenomenology of intrusive sexual thoughts in these populations. The importance of this distinction is further reinforced when one considers the recognised treatment protocols for intrusive sexual thoughts. Current treatment models for sexual offenders aim to increase salience, intensity and frequency of unpleasant thoughts in order to increase distress and subsequently prevent recidivism (Marshall and Langton, 2005). Contrastingly, the emphasis of treatment for obsessive compulsive disorder is placed on reducing the importance and responsibility individuals place on their thoughts (Salkovskis, 1985). Given that existing research evidence highlights the increased likelihood and detrimental consequences of misdiagnosing intrusive sexual thoughts (Veale *et al.*, 2009; Glazier *et al.* 2013), the current paper aims to highlight the phenomenological similarities and differences between populations to aid clinicians in a differential diagnosis.

Preliminary examination of the literature suggests that there two key distinctions which can helpfully inform any review. These are (i) ego-dystonic vs ego syntonic and (ii) intrusive cognitions vs appraisals. The term ego-dystonic refers to internal content (e.g. values and feelings) that are experienced as inconsistent or in conflict with the individual's belief system and sense of ideal self. Contrastingly, ego-syntonic describes internal experiences that are in harmony with one's belief system (Salkovskis, 1985). The ego-dystonicity of thoughts has been recognised as a key differential characteristic that dictates how intrusive sexual thoughts are experienced (Belloch *et al.*, 2004). In general, sex offenders reportedly experience sexual thoughts as ego-syntonic (e.g. purposely, internally derived and result in pleasure or gratification) whilst clinical populations experience thoughts as ego-dystonic

(e.g. intrusive, unacceptable and aversive) (Purdon and Clark, 1993; Byers *et al.*, 1998; Gordon, 2002; Lee and Kwon, 2003). Secondly, a debate exists within the literature around whether it is the intrusive thought itself that is problematic or whether it is the interpretation of the thought that dictates how it is experienced. So far, research has noted that the way in which thoughts are appraised for meaning is vital in identifying their likelihood of escalation (Salkovskis and Kirk, 1989; Freeston, Rhéaume and Ladouceur, 1996). However, can this criterion be used as a means of discriminating between these thoughts in clinical and forensic populations?

Review Questions

1. How do current theoretical models explain the onset and maintenance of intrusive sexual thoughts?
2. What are the similarities and differences in the cognitive process, content and interpretation of intrusive sexual thoughts across these populations?

Main aims and objectives

To explore existing literature on the thought processes in sex offenders and compare findings with existing research from clinical and non-clinical populations. In order to do this, the current literature on intrusive sexual thoughts were considered. The phenomenology of intrusive sexual thoughts was explored in four stages.

Firstly, existing literature concerning the cognitive processes, content and appraisals of intrusive sexual thoughts in the general and clinical populations will be described. Secondly existing understanding of the thought processes of sexual offenders will outlined and considered in terms of their ability to explain intrusive sexual thoughts in this population. Thirdly, the review will then evaluate and compare the similarities and differences in the phenomenology of intrusive sexual thoughts, across these populations. Finally, findings will be discussed in relation to clinical and research implications for working with intrusive sexual thoughts.

Methodology: Design and Protocol

A series of literature searches were conducted to identify relevant studies for a narrative review. The online databases PSYCNET, Scopus and Web of Science were searched, using a combination of the following terms: unwanted thoughts, intrusive thoughts, intrusive sexual thoughts, sexual obsessions and sexual preoccupation. Index terms within databases were

also used to focus search criteria. Only articles referring to adult males were included in the review, as there are good reasons to believe that there are important gender differences in both the content and probably the processes involved¹. No restrictions were set regarding publication date for studies. Reference sections of the identified papers were also scrutinised for additional studies.

A total of 505 papers were identified, with 53 meeting the following eligibility criteria (dated from 1993 – 2014) once duplicates were removed.

1. Papers attempted to define or investigate intrusive sexual thoughts, their cognitive processes, development, content or interpretation.
2. Participants included sex offenders, those with Obsessive Compulsive Disorder or the general population
3. Participants were adult males
4. Papers were written in the English Language
5. Papers were published in peer reviewed journals

Although a systematic search was undertaken, the papers identified were reviewed narratively. The main aim of a narrative review was to collate and evaluate existing information on intrusive sexual thoughts in sex offenders and compare findings to research from both clinical and non-clinical populations. Preliminary literature searches suggested that little research has been done to directly compare intrusive sexual thoughts in the selected populations. It was therefore believed that a narrative review best reflected the feasibility of the research question. Consequently, the review does not provide a comprehensive analysis of the quality of the literature, but aims to present an overview and synthesis of existing knowledge in an effort to deepen our understanding of intrusive sexual thoughts in sex offenders. However, a summary table of the empirical papers used in the review can be found in appendix 1 to provide more detailed information about the included studies.

¹ For the purpose of the current review, a broad definition of sexual offender was used, typically referring to an individual who had perpetrated a crime covered by the Sexual Offences Act 2003. As men account for the majority of perpetrators of sexual offences committed in England and Wales (Ministry of Justice report, 2013), the current review focussed exclusively on males.

Results

Current theoretical understanding of intrusive sexual thoughts in the general and clinical populations: Normal or Abnormal?

The main theoretical focus of research in this field has been to differentiate between problematic and unproblematic intrusive thoughts. Existing literature notes that although the experience of intrusive thoughts is universal, only a small proportion develop to clinical levels (Rachman, 1971). Thus, it has been suggested that clinical obsessions are an extreme variation of a common cognitive event (Clark, 2005; Morillo *et al.*, 2007). The majority of evidence in this area pertains specifically to OCD². However, experiencing intrusive thoughts alone does not indicate the presence of clinically significant obsessions or indeed OCD.

Current understandings hypothesise that the way in which thoughts are appraised is paramount in determining whether they escalate into clinical obsessions (Salkovskis and Kirk, 1989; Freeston, Rhéaume and Ladouceur, 1996). This continuum hypothesis forms the premise of current cognitive theoretical models of OCD. Within this approach an emphasis is placed on the role of beliefs in fusing intrusive thoughts to events or actions (Rachman, 1998). According to Salkovskis (1996) these beliefs are twofold. Firstly, individuals believe that experiencing the thought is an indication of responsibility for harm towards oneself or others. Secondly the individual believes that taking action through direct thought control strategies will help to neutralize their inflated sense of responsibility. These neutralisations are characterised by a sense of over-control and preoccupation. Thoughts are often formed as hypothetical and thus difficult to disprove (Rachman, 1998). This quest to prove the unprovable produces anxiety, doubt, reassurance seeking and compulsions (Salkovskis, 1985). Possession of these maladaptive beliefs therefore overestimates the significance of the thought for the individual and promotes threatening interpretations about their presence (Salkovskis, 1996).

It has been argued that in addition to dysfunctional beliefs, escalation to clinical obsessions exists on a continuum of severity (Clark and Rhyno, 2005; Berry and Laskey, 2012). In general, clinical obsessions are believed to be experienced at an increased frequency, cause greater

² Individuals with OCD suffer from obsessions which are recurrent and persistent thoughts, impulses, or images that are experienced as intrusive and inappropriate. These obsessions are usually accompanied by behavioural compulsions that aim to prevent or reduce any anxiety or distress caused (American Psychiatric Association, 1994).

levels of distress and are perceived as less controllable than intrusive thoughts (Rachman *et al.*, 1971). Therefore, the way in which one interprets and tries to control unwanted intrusive thoughts determines whether they become problematic (Radomsky *et al.*, 2014). Additionally, it has been noted that it is common for an individual experiencing intrusive thoughts to display obsessions and compulsive behaviours in other domains (e.g. washing, checking, order) (Veale *et al.*, 2009).

Alternative theoretical perspectives have been developed to explain the occurrence of cognitive products within OCD. Wells (1997) in his Cognitive Model of OCD proposed that intrusive thoughts activate metacognitive beliefs which in turn initiate maladaptive processing. Thus, intrusions are misinterpreted due to metacognitive beliefs about the dangerousness and significance of thoughts and the fear that thoughts are fused with actions. The nature of these metacognitive beliefs activates negative appraisals of thoughts, causing the individual emotional distress and worry. In an effort to reduce the discomfort caused, the individual is prone to using neutralizing techniques and ritualistic or compulsive behaviours (Wells, 1997). However, several qualitative differences have been noted in the literature between intrusions and worry. Differences centre around the trigger for the thought, the cognitive manifestation (e.g. verbal or visual), ability to resist and the acceptability of thoughts experienced (Turner, Beidel and Stanley, 1992). Differentiations between worry and intrusive thoughts as cognitive phenomena therefore mean that it is problematic to apply this theory to the issues discussed here. Similar to negative automatic thoughts, worries are believed to operate on an ego-syntonic mechanism (Turner, Beidel and Stanley, 1992; Salkovskis and Millar, 2016) and thus are characteristically different to intrusive thoughts. Similarly, the inference model put forward by O'Connor and colleagues (2005) emphasises the importance of processing in the cognitions of OCD sufferers. The authors proposed that cognitions stem from initial doubts and inferences. Within this framework, obsessional doubts are inferred on the basis of an invalid reasoning. Therefore, the theory is less focussed on specific mental content, and emphasises the processes that form the justification for a particular doubt (O'Connor, Aardema and Pélissier, 2005; O'Connor, Ecker, Lahoud and Roberts, 2012). Whilst these theories are useful in helping us understand the cognitive products and processes involved in OCD, they are relatively silent on the content of thoughts.

One theory that does consider the importance of thought content was Salkovskis's (1985) cognitive behavioural theory. Within this framework, an increased emphasis is placed on the

importance of the thought itself and the meaning attached to it. According to Salkovskis (1985) it is this appraisal of the thought content that is key to understanding the escalation of intrusive thoughts to clinical obsessions. Salkovskis suggested that cognitively, clinical obsessions are caused by a catastrophic misinterpretation about the significance of the thought. Thus responses to this cognitive stimulus are linked to one's beliefs about being responsible for harm coming to self or others, this being the "bridge" between the occurrence of intrusions and the compulsive/neutralising actions. The individual therefore takes either overt or covert action in an attempt to neutralise the thought or prevent the undesired action (Salkovskis, 1985). Since its inception, the cognitive behavioural approach to understanding clinical obsessions had generated much literature. More recent adaptations to the model highlight the importance of negative mood states, mental control and ego-dystonicity in the interpretation and meaning attributed to intrusive thoughts (Salkovskis and Millar, 2016; Clark and Purdon, 2016).

Current evidence indicates that intrusions can become problematic for individuals if they are experienced as ego-dystonic. However, it is the perception and worry that thoughts may be ego-syntonic that typically drives obsessional behaviours. The next section will look at this cognitive process in more detail.

Current understanding about the process of intrusive sexual thoughts: Positive vs Negative appraisals?

Distinguishing between sexual cognitions that are exclusively positive or negative may not be as straightforward as first thought. According to Renauld and Byers (1999), interpreting the content of intrusive sexual thoughts alone is insufficient for differentiating between positive and negative cognitions. The authors studied the frequency, diversity, and content of university students' sexual cognitions. Findings highlighted similarities in the content of intrusive sexual thoughts, whilst differences were noted in the most commonly experienced positive and negative cognitions. Commonly reported positive sexual cognitions were; having intercourse with a loved partner, kissing passionately, making love outside the bedroom, and taking someone's clothes off. Contrastingly, the most commonly reported negative sexual cognitions were; having intercourse with someone familiar (whom they had not had sexual relations with), being embarrassed by failure of sexual performance, having sex with a stranger and being overwhelmed by a stranger's sexual advances (Renauld and Byers, 1999).

Rachman (1998) suggested that whether one appraises the content of thoughts as upsetting is determined by the person's value system. Thoughts of a sexual nature are believed to be amongst the most upsetting form of intrusive thought, and one of the most commonly self-generated for both clinical and nonclinical populations (Purdon and Clark, 1994; Clark, Purdon and Byers, 2000; Rowa and Purdon, 2005). It has also been suggested that intrusive thoughts that centre on less socially acceptable, more morally reprehensible content are liable to be mistaken for significant pathology and thus may cause increased shame and fear of negative consequences. Consequently, individuals may be less likely to disclose such thoughts (Simonds and Thorpe, 2003). Similarly, disclosure of intrusive thoughts about sexual themes are associated with more social rejection, perceived as less acceptable and therefore might be more stigmatizing for individuals to disclose than other types of obsessions (Cathey and Wetterneck, 2013). Resultantly, intrusive sexual thoughts may be underreported, under-recognized, and under treated (Cathey and Wetterneck, 2013).

Radomsky *et al.* (2014) noted that although repugnant intrusions may be less frequently reported; they are perceived as the most difficult to control. Perceived inability to control thoughts was exacerbated when individuals worried about acting on the thought, and if the thought was experienced as arousing (Clark, Purdon and Byers, 2000). Purdon and Clark (1994) found that the extent to which individuals believed they could act on their thought in real life was closely related to both the frequency and persistence of the intrusion as well as its perceived uncontrollability (Purdon and Clark, 1994).

So, it is apparent within the OCD literature that the appraisal process is key to understanding whether an intrusive thought causes distress. Evidence suggests that it is not the content of the thought itself that results in distress, but how the thought is appraised that is important. Next we turn to exploring what existing literature states about the cognitive processes of sex offenders.

Current theoretical understanding of intrusive sexual thoughts in sex offenders: Differentiating them from “the norm”

Historically, explanations of sexual offending have adopted more of a behavioural perspective attempting to understand how sex offenders act as being a consequence of pathology or mental health. It wasn't until the 1970's that researchers began to consider the link between cognitive processes and sexual offending (Terry, 2013). Theoretically, the underlying question was to establish whether sexual offender's cognitions facilitated their

offending (Ward and Casey, 2010). Academically this led to a fascination with differentiating between “normal” cognitions and those of sexual offenders (Gannon, 2009). The first researchers to apply this notion to sexual offenders were Abel and colleagues who defined this phenomenon as “cognitive distortions” (Abel, Becker and Cunningham-Rathner, 1984; Abel, Gore, Holland, Camp, Becker and Ratner, 1989). Since this pioneering work, the concept of cognitive distortions has been a major focus of research attention in the sexual offending literature. O’ Ciardha and Ward (2013:6) defined cognitive distortions as *“specific or general beliefs/attitudes that violate commonly accepted norms of rationality, and which have been shown to be associated with the onset and maintenance of sexual offending”*. The content of these distortions varies depending on the proclivities of the offender.

Distortions were believed to develop as a consequence of conflict between external reinforcements (i.e. perceived societal norms) and self-condemnation, producing a form of cognitive dissonance (Gannon and Polaschek, 2006). The function of distortions was therefore to alleviate distress to the offender when they realised they had violated societal norms, thus minimising any subsequent guilt or anxiety at one’s actions (Ward and Casey, 2010). A major drawback of this conceptual understanding was that it assumed sexual offenders possessed relatively stable, offense supportive beliefs, with little attempt to theoretically explain the presence of and mechanisms responsible for their generation (Ward, 2000; Gannon, 2009). Conflicting evidence has been documented about the origins of these distortions; with some research indicating they are fixed biological traits, and others suggesting they can be situationally influenced (Heckert and Gondolf, 2000).

One attempt to understand the origins of cognitive distortions was made by Ward and Keenan (1999). The authors suggested that cognitive distortions emerged from a set of underlying schemas that influenced the interpretation of processed information. Documented schemas included representations of the victim, their needs and desires, beliefs and attitudes (Ward, 2000). Activation of these schemas meant that ambiguous information was processed in a way that was consistent with the offenders underlying schema (Ward and Keenan, 1999). Frequent exposure to schema activating situations thus reinforces the biased interpretation, strengthening the association over time and increasing the use of this information processing pathway (Pettit, Polaha, and Mize, 2001). It has been documented that the nature of these biased interpretations increases the likelihood of sexual offending, allowing deviant sexual behaviour to be perceived as more appropriate, necessary or appealing (Mann and Beech, 2003).

Despite intense academic interest, little consensus has been reached on the operational definition of cognitive distortions in this population. This lack of clarity has created a “definitional impasse” in the conceptualisation (Ward and Casey, 2010:50). This has meant the term has been used inconsistently throughout the literature referring to (i) underlying offender beliefs and attitudes, (ii) adaptive cognitive operations, (iii) post-offense rationalisations as well as, (iv) techniques that serve to deny, minimize, rationalize, or justify the behaviour (Abel *et al.*, 1989; Blumenthal, Gudjonsson and Burns, 1999; Ward and Keenan, 1999; Ward, 2000; Maruna and Mann, 2006).

Existing evidence therefore suggests that sexual offenders interpret sexual information in maladaptive ways, usually in a manner consistent with their underlying beliefs. However, inconsistencies in the terminology used and application of this theory has meant that it has become blurred with cognitive operations. This review shall now go onto outline what existing literature tells us about the cognitive processes of sexual offenders.

Current understanding about the process of sexual thoughts in sex offenders: Wanted or Unwanted?

Current research evidence suggests that due to their maladaptive beliefs (or cognitive distortions), sex offenders process sexual information in a manner that is consistent with their offence supportive views. The main focus has been to link offending behaviour to the use of adaptive information processing strategies that help offenders legitimise their actions (Abel *et al.*, 1984/1989; Pryor and Stoller, 1994; Ward *et al.*, 1997). Two key themes have been identified from the literature namely (i) that the content of sex offender thoughts are more deviant and (ii) that sex offenders have a particular predisposition to hyper-sexuality and sex addiction. Little research has been conducted into the potential that sex offender’s thoughts could be experienced as ego-dystonic. However, what research has been conducted will be considered.

“Deviant” Sexual interests and Hypersexuality

Sexual revulsion is considered the polar opposite of sexual interest (Moser, 2001). Consequently, one might assume that you cannot experience these two concepts simultaneously. Much of the literature suggests that sex offenders possess a particular interest for sexual activity, often referred to as being hypersexualised, obsessed, addicted or preoccupied (Fong, 2006). Unfortunately, in a similar vein to cognitive distortions, these terms have been used interchangeably in the literature, making operational definitions and

comparisons complicated.

The focus of research in this area has investigated whether the content of sex offenders' thoughts are different, whether they have a higher frequency of thoughts or whether qualitative differences exist in the deviant nature of offenders sexual interests. It can be presumed that due to their offending nature, sex offenders find sexually themed material highly salient and thus may experience sexual thoughts as ego-syntonic (Smith and Waterman, 2004).

It has been noted that in general, sex offenders hold relatively traditional, conservative attitudes and beliefs about their victims (Howells and Wright, 1978; Scott and Tetreault, 1987). According to Hanson *et al.* (1994) these beliefs tend to be more controlling and aligned with views of sexual entitlement. There has been a general consensus in the literature that sex offenders are more likely to be pre-occupied with sexual thoughts and behaviour (Hanson and Harris, 2003). Increased levels of sexual preoccupation have been linked to a higher sex drive and are considered risk factors³ for sexual recidivism (Giambra and Martin, 1977; Byers *et al.*, 1998; Hanson and Harris, 2000). Furthermore, sex offenders who are sexually preoccupied are more likely to meet criteria for sex addiction (Marshall and Marshall, 2006).

Much debate exists in the literature as to whether sex offenders display a higher level of sexual interest than the general public. Estimates for sex addiction in sex offenders have been documented around 50 per cent or nearly three times higher than non-offenders (Carnes, 1989; Blanchard, 1990; Marshall and Langton, 2006). Definitional discrepancies across research studies means that results should be treated with caution; however, it can be assumed that a significant number of sex offenders may be classified as sex addicts (Marshall, Marshall, Moulden and Serran, 2008). Hypersexuality in particular has been identified by the presence of excessive, frequent and intense sexual fantasies that are accompanied by excessive masturbation⁴ and high numbers of sexual partners (Langstrom

³ Two types of risk factors are acknowledged in the literature, those that are relatively stable and those that are liable to fluctuate (Gordon and Grubin, 2004). Static risk factors include such things as previous sexual convictions, previous criminal record, age and lack of stable intimate relationships and are considered relatively stable. Sexual interests and distorted attitudes would be considered dynamic risk factors, which means they are subject to change and are associated with likelihood of reoffending (Thornton, 2002). Combining static and dynamic risk factors allows the assessor to decide whether offenders fall into a low, medium, high or very high risk group (Thornton *et al.*, 2003).

⁴ According to Kafta (1997) hypersexuality is characterised by a minimum of seven orgasms per week and an average of one to two hours a day engaged in sexual activity. These symptoms should be present for at least 6 months, and cause personal distress or adverse consequences for the individual.

and Hanson, 2006; Kingston and Bradford, 2013). Despite attempts to quantify both sexual addiction and hypersexuality, both concepts require a normative judgement to be made around what is considered problematic and what is considered within the normal realms of a healthy sex drive. Furthermore, these two concepts are behavioural in nature, with little attention being given to the cognitive processes involved.

One area in which distinctions have been made between these concepts is in the assessment literature. Sex offender treatment programmes in the UK differentiate between sexual interests that include preoccupations and sexual preferences, and distorted attitudes and beliefs that encompass cognitive distortions and offence supportive beliefs (Thornton, 2002)⁵.

Research in this field has therefore suggested that sex offenders may be more likely to think about sex more, have more sexual partners and fantasise about materials that would typically be seen as deviant. It has also been suggested that sex offenders possess a set of distorted beliefs that allow them to experience sexual thoughts as ego-syntonic. Thus far, research has not suggested that sex offenders would find sexual thoughts intrusive, in fact, the opposite is true that sex offenders enjoy sexual thoughts. This review now goes onto to think about what we know about intrusive thoughts in this population.

Intrusive thoughts in Sex Offenders

Research has attempted to explain sexual offending in terms of what is abnormal or distorted within the mind of an offender. Yet much of the research outlined contains overlapping concepts and processes across these varied populations. Despite the commonalities across the literature, Marshall and Langton (2005) are one of the only researchers to suggest that sex offenders experience intrusive thoughts that are similar in nature to those identified in the clinical literature. The authors acknowledged the possibility that some sex offenders may suffer with unwanted, distressing and ego-dystonic thoughts in which they exercise limited control. Specifically, Marshall and Langton (2005) identified three possible areas in which sex offenders could experience intrusive thoughts namely; (i) negative self-appraisals, (ii)

⁵ Assessment of sex offenders includes gathering a full psychosexual history of both sexual cognitions such as fantasies and sexual behaviour. This includes identifying any signs of hypersexuality (i.e. frequent masturbation or numerous sexual partners) and of sexual preoccupation or rumination (frequent or intrusive sexual fantasies, or subjectively uncontrollable sexual urges) (Gordon and Grubin, 2004).

ruminations and (iii) deviant sexual thoughts.

Firstly, offenders experience negative, derogatory self-appraisals. These occur in high frequencies and are experienced as unbidden, and unwanted. The impact of these consistent negative self-appraisals is a feeling of sadness and helplessness which influences an offender's self-esteem. Negative mood states such as loneliness, inadequacy, and humiliation have been linked to the onset of overwhelming and irresistible deviant sexual fantasies and associated masturbatory activities (McKibben *et al.*, 1994). Furthermore, these thoughts are believed to be particularly poignant and noticeable when offenders are under stress, increasing the likelihood of offending (Hanson and Harris, 2000).

Secondly, Marshall and Langton (2005) noted that offenders experience ruminations and worries about being detected, identified, prosecuted and imprisoned. These thoughts are often perceived as undesirable, unwanted, catastrophic and difficult to control. The authors suggest that whilst unpleasant, offenders go through a process of systematic desensitisation to intrusive thoughts that in the absence of negative consequences become reinforced. Furthermore, it has been documented that the effects of punishment are significantly reduced when it follows a highly reinforced behaviour (Domjan, 1998). This is important when one considers that often sexual acts of sex offenders are associated with highly pleasurable and arousing experiences, which makes them difficult to control (Singer, 1975). The habituated relationship between sexual thoughts and pleasure therefore means that one might anticipate an increase in sexually deviant thoughts (Marshall and Langton, 2005).

Thirdly, Marshall and Langton (2005) acknowledged that some sexual offenders are distressed by the intrusive sexual thoughts themselves, and try worriedly to inhibit or prevent them. Although thoughts can be situationally cued, and fleeting, they may also be persistent, associated with negative mood states and be self-generated. However, the authors stated that in their extensive clinical experience, only 5-10% of their sex offender clients had requested help in dealing with uncontrollable intrusive sexual thoughts and urges. Moreover, the authors proposed the possibility that sexual thoughts of sex offenders are only experienced as intrusive, at the beginning of their career. During this period of time, the distress caused by intrusive sexual thoughts may be identified as ego-dystonic and therefore create a situation of cognitive dissonance. In contrast to this, Hudson, Ward and McCormack (1999) reported that some sex offenders view their offending positively. For these offenders' deviant sexual thoughts are experienced as neither intrusive nor distressing, they deliberately initiate and enjoy them, dismissing and minimising any harm caused to

victims.

In his work on OCD, Salkovskis (1989) outlined that intrusive thoughts are more likely to become obsessive in nature when the threat posed by the thought holds a personal sense of responsibility for harm (to self and/or others). Marshall and Langton (2005) suggest that whilst the post offense rationalisations of sex offenders are similar to obsessions, they are limited in duration and situationally cued; they may in fact be better considered to be related to feelings of regret. The authors also state that the consequences for sex offenders are quite realistic, as opposed to the hypothetical catastrophic worries of OCD sufferers. Given this criteria, it is possible that the intrusive thoughts and images experienced by sexual offenders possess more resemblance to Rachman's (1973) notion of morbid preoccupations. According to Rachman, morbid preoccupations occur when a thought has a rational basis or concerns realistic problems that cause distress. The author suggests that these thoughts are ego-syntonic with the individual's sense of self and therefore do not evoke the same resistance as seen in obsessional thoughts of OCD patients. Morbid preoccupations have been considered to be repetitive in nature to the exclusion of other mental activities causing difficulties in maintaining concentration (Salkovskis and Warwick, 1986).

Similarities and Differences in Intrusive Sexual Thoughts: OCD vs Sex Offenders

Findings of the current review indicated that some similarities exist in the experience of intrusive sexual thoughts in those with OCD and sex offenders. Specifically, comparative understandings were noted in (i) the theoretical explanations, (ii) thought content and (iii) cognitive operations utilised. Evidence presented here suggests that theoretically, intrusive sexual thoughts are a by-product of maladaptive belief systems held by individuals, however the nature of underlying beliefs are distinct. Similar thought content and cognitive operations used to neutralise the threat posed by the thought were noted, however the motivation and intent behind these cognitive events differed. Furthermore, differences have been reported in (i) the appraisal of the thought and (ii) the underlying schemas or beliefs held by the two populations in terms of ego-syntonicity. In OCD, the appraisal of the thought is considered ego-dystonic but it is the worry that the thought is ego-syntonic that causes them distress. Conversely, literature on sex offenders suggests that thought appraisals are ego-syntonic and any distress caused is a by-product of concerns about getting caught.

PHENOMENOLOGY OF INTRUSIVE SEXUAL THOUGHTS	
SIMILARITIES	DIFFERENCES
<ul style="list-style-type: none"> • Theoretical explanation (maladaptive beliefs/schemas) • Thought content • Cognitive processes (secondary appraisals) <ul style="list-style-type: none"> • Use of cognitive operations to minimise threat/distress 	<ul style="list-style-type: none"> • <i>Ego-syntonicity of thoughts</i> • <i>Behavioural response to thoughts (e.g. masturbating or acting on thoughts)</i> • <i>Avoidance vs approach behaviours</i> • <i>Efforts to suppress thoughts</i> • <i>Frequency and intensity of thoughts</i> • <i>Level of distress, anxiety or guilt</i> • <i>Over-disclosure of past sexual history</i> • <i>Help seeking behaviour</i> • <i>Presence of other OCD symptoms</i> • Appraisal/interpretation of thought

Figure 1: Similarities and differences in phenomenology of intrusive sexual thoughts in OCD and sex offenders from the current paper combined with Veale *et al.*'s (2009) findings

As noted previously, Veale and colleagues (2009) made some useful initial contributions to the phenomenology of intrusive sexual thoughts, specifically in regards to the dilemma of differential diagnosis. Figure 1 above combines Veale *et al.*'s (2009) contributions (indicated in bold italics) and current findings. Results from the current review indicate that some of Veale *et al.*'s (2009) differentiating characteristics may not be as straightforward as first thought. What follows is a discussion of areas of inconsistency and potential misclassification that were highlighted in the literature.

Making a Differential Diagnosis between OCD and Sexual Offenders

So far this review has highlighted what existing literature tells us about intrusive sexual thoughts. Whilst the evidence presented has indicated that some qualitative similarities and differences exist between the populations, there are also specific areas that have created confusion.

One area that has been particularly misconstrued is the association between sexual arousal and intrusive sexual thoughts. It has been well documented that sex offenders experience sexual gratification or arousal from their deviant sexual thoughts. However, it has also been

recognised that sexual offender preferences can fluctuate. Evidence also suggests that sex offenders have the ability to temporarily suppress their sexual arousal to preferred taboo stimuli whilst inducing their arousal for acceptable (non-preferred) stimuli by using cognitive strategies like mental imagery (Marshall, 2006; Muller *et al.*, 2014). It has been acknowledged however, that inhibiting sexual arousal is easier than generating sexual arousal (Lykins *et al.*, 2010). It is important to note that much of the literature on sexual arousal in sex offenders is based upon either self-report from offenders themselves or physiological measurements of the biological sensations of arousal⁶, both of which have questionable validity.

However, whilst evidence suggests that sex offenders may be more inclined to get aroused by sexual material, it has been documented that other populations also experience arousal to aversive materials and therefore, this may not be an accurate representation of sexual interest.

On the contrary, evidence suggests that sexual obsessions that occur as part of OCD do not serve a sexual function at all. According to Gordon (2002) they are rarely sexually arousing, and seldom lead to behavioural enactment of the thought. Owing to the fact that the sufferer perceives the thoughts as immoral, they pathologically exaggerate the significance of the thought and exhibit avoidance behaviours towards identified triggers (Veale, *et al.*, 2009). This may mean that someone with OCD may be vulnerable to over report perceived arousal (Warwick and Salkovskis, 1990). Existing literature suggests that individuals with OCD may therefore consistently monitor and check for evidence of sexual arousal. This heightened awareness creates a process of selective attention resulting in a feedback loop that subsequently increases blood flow and level of arousal (Veale *et al.*, 2009).

This contrasts with accounts suggesting that people with OCD may in fact experience sexual arousal in response to intrusive thoughts. Warwick and Salkovskis (1990) documented that perceived and actual physical sexual arousal can occur in patients with OCD. The authors noted that individuals can experience intrusions during sexual activity or as a result of an erection. Further support for this notion was documented by Veale *et al.* (2009) who

⁶ Penile plethysmography (PPG) or phallometry is considered the gold standard for objective measurement of sexual interest in men (Muller *et al.*, 2014). PPG involves the observation and measurement of penile circumference in response to sexually arousing stimuli (Banse, Schmidt and Clabour, 2010). The technique has been criticised for being overly intrusive with concerns raised about the ethical implications, validity and reliability of usage (Simon and Schouten, 1993; Gordon and Grubin, 2004; Kalmus and Beech, 2005).

outlined that people with OCD may experience unwanted intrusions during masturbation to socially acceptable adult literature, and become confused as to whether the thoughts are ego-dystonic or ego-syntonic. Additionally, the physical sensations of anxiety and sexual arousal are considered to be comparable. Therefore, it is possible that the anxiety associated with sexual thoughts could be misinterpreted as a sign of sexual arousal. Attributing this experience as an indication of sexual arousal may then reinforce individuals' concerns about acting on the thought. This in turn might promote greater effort to suppress thoughts (Clark, Purdon and Byers, 2000). Similarly, Bancroft (1974) noted that an increase in sexual arousal can also follow exposure to an aversive stimulus. It is therefore possible that individuals may also become aroused by negatively associated stimuli.

Another area which creates confusion is when obsessional behaviours present as sexual behaviours. According to Veale *et al.* (2009) people with OCD might appear to act on their obsessional urge as form of checking behaviour. However, the authors note that this is very rare and does not cause significant harm. Checking behaviours in OCD are believed to be the result of an inflated sense of responsibility for harm felt by the individual. Described as compulsions, the aim of the behaviour is to neutralise the discomfort experienced at having a thought one perceives as repugnant (Salkovskis, 1999). Compulsions themselves are defined as repetitive behaviours or mental acts that the person feels driven to perform (Veale, 2004). There is some debate in the literature as to whether individuals with OCD can experience pleasure from these rituals. Whilst some outline that a lack of pleasure differentiates compulsions from other impulsive acts (Veale, 2004), others state that it is possible that some individuals find pleasure in the performance of rituals (Salkovskis, 1985). However, it is noteworthy that any pleasure derived from the completion of compulsions could be linked to the reduction in distress. Figure 2 below illustrates these areas of potential confusion.

AREAS OF CONFUSION/OVERLAP

- Ego-syntonicity of thoughts: Debate in the literature as to whether this is a static or dynamic factor. It has been considered to be related to underlying schemas but could also be contextually driven
- Sexual arousal: Has been documented in both populations. Also suggestions made that sexual arousal is a poor indication of sexual interest and that it is often confused with anxiety.
- When obsessional behaviours present like sexual behaviours. It has been noted that occasionally those with OCD will demonstrate checking behaviours in an effort to neutralise distress. Whilst behaviourally this presents similar, the motivation and intent behind the behaviour is different in both populations, but often confused.

Figure 2: Identified areas of potential confusion/misdiagnosis in intrusive sexual thoughts between OCD sufferers and sexual offenders

Discussion

The aim of the current review was to highlight the phenomenological similarities and differences in intrusive thoughts in OCD and sex offending to aid clinicians in a differential diagnosis and prevent detrimental miss-classification. Findings indicated that there are some similarities and differences between these populations. Specifically, parallels have been drawn between the theoretical explanations, content and cognitive processes whilst discrepancies have been noted in the ego-syntonicity and appraisals of intrusive sexual thoughts.

Existing understanding of intrusive thoughts (including verbal thoughts, images and impulses) is that they are a set of common cognitive events within our stream of consciousness (Clark and Purdon, 1995). Individuals with OCD, (by virtue of maladaptive beliefs) overestimate their sense of *responsibility for harm* to self or others (Salkovskis, 1985). This may mean they react particularly strongly to a subset of intrusions which are discordant to their fundamental beliefs concerning responsibility for harm. Sex offenders are characterised by a quite different set of cognitive distortions that cause them to develop a preoccupation with sexual material (Ward and Casey, 2010), *with little or no regard to harm*.

Whilst the focus of these two conceptualisations is different, the function of cognitive operations in both samples is reportedly a desire to meet motivated goals, but of quite different types. Hence, theoretically, both phenomena can be seen as the result of maladaptive belief systems.

In line with Renauld and Byers (1999), evidence from the current review indicated that interpreting the content of intrusive sexual thoughts alone was insufficient for differentiating between populations. Thoughts of a sexual nature have been reported amongst the most upsetting and one of the most commonly self-generated for both clinical and nonclinical populations (Purdon and Clark, 1994; Clark, Purdon and Byers, 2000; Rowa and Purdon, 2005). Further similarities can be drawn between the cognitive processes of intrusive sexual thoughts.

Research has suggested that in both populations cognitive operations exist with the aim of reducing any distress, tension, anxiety or discomfort caused by the thought. Although in OCD meaning rather than distress motivates. This means that, to avoid harm and responsibility for it, people with OCD are prepared to tolerate increased discomfort. Cognitive strategies in the form of justifying and minimising personal responsibility can be considered normal, acceptable responses in reaction to a distressing situation. In OCD, these strategies include reassurance seeking, checking behaviours, avoidance and mental rituals (Salkovskis, 1985). In contrast, cognitive strategies used by sex offenders are directed towards gratification, with secondary phenomena which could be described as justifications and minimisations, and perceived as a further indication of intent (e.g. Abel *et al.*, 1989; Ward and Keenan, 1999). It has been speculated that cognitive strategies in sex offenders may serve the same function as in other populations, similar to the neutralisation techniques outlined by Rachman (1998). It has been suggested that repeated exposure to intrusive sexual thoughts leads to a process of desensitisation in sex offenders, where cognitive dissonance is relieved and thoughts become acceptable to the individual (Byers *et al.* 1998). According to this view, sex offenders may navigate this process, eventually reaching acceptance of their thoughts. It is also clear, however, that OCD sufferers, apart from experiencing a higher frequency of thoughts than other populations, experience a worsening of distress with increased exposure. This suggests there may be a fundamental difference in the experience of thoughts and that simply reflecting on the cognitive processes involved may not be beneficial.

One of the main distinguishing features of intrusive sexual thoughts between clinical and forensic populations has focussed on whether thoughts are wanted or not? Existing evidence

has highlighted that people with OCD find intrusive sexual thoughts ego-dystonic (Salkovskis, 1985) whilst sex offenders find them ego-syntonic (Smith and Waterman, 2004). Whilst no direct research has been conducted to make this comparison, we can assume from what we do know about sex offender cognitions that this is the case. The general consensus from existing research is that the majority of sex offenders display a preoccupation with sex, they have more sexual partners and are more likely to be addicted to sex (Giambra and Martin, 1977; Byers *et al.*, 1998; Hanson and Harris, 2000; Marshall, Marshall, Moulden and Serran, 2008). However, it has been illustrated here that the boundary between ego-syntonic and ego-dystonic sexual thoughts may be less distinct than previously reported (Clark, Purdon and Byers, 2000). Situational and contextual factors may therefore impact on how one perceives and interprets sexual cognitions (Byers *et al.*, 1998). This may mean that using subjective interpretations of sexual cognitions may be a poor indication of sexual preference. These variations in the perceived acceptability of sexual cognitions draw into question the criteria used to assess and diagnose intrusive sexual thoughts in sex offenders. If we recognise that the acceptability of one's thoughts may vary, then how can assessing the ego-syntonicity of sexual thoughts in sex offenders provide any meaningful data for a differential diagnosis?

Finally, evidence from the review highlighted significant differences in the appraisal process of OCD sufferers and sex offenders. In general, research indicates that whilst anxiety may be elicited in sex offenders, it is not as a direct result of the thought, but a worry about the consequence of the thought (Gordon, 2002; Lee and Kwon, 2003, Veale *et al.*, 2009). However, evidence has been put forward that sex offenders' appraisals mirror those of other populations, whilst contradictory evidence has shown that offenders' interpretations are positive in nature (Hudson, Ward and McCormack, 1999; Marshall and Langton, 2005). It is clear therefore that the appraisal process associated with intrusive sexual thoughts may be more complex than first thought.

Potential Theoretical Explanation for Findings

The current review provides some theoretical suggestions to explain this discrepancy. It is purported that the cognitive process involved in intrusive sexual thoughts can be differentiated by the amalgamation of Ward and Kennan's (1999) Schema Theory and Salkovskis's (1985) Cognitive Model of OCD. Using this framework, it is proposed that the process of the initial intrusion is comparable in both populations. The author suggests that in the immediate aftermath of the thought, a primary evaluative process takes place. It is in

this primary appraisal process that differences may be seen between sex offenders and other populations (figures 3 and 4 below illustrate this process diagrammatically). Primary appraisals are processed in concordance with individuals underlying beliefs and schemas. As such, this means that ambiguous information becomes processed in a way that is consistent with existing idiosyncratic beliefs.

Thus for those with OCD who possess maladaptive beliefs around their responsibility for harm, the thought is appraised as ego-dystonic. Resultantly, as the appraisal of the thought is repugnant, this causes the individual to become anxious, ruminate and attempt to avoid the trigger situation often displaying safety seeking behaviours. Alternatively, a sex offender evaluates the thought as ego-syntonic, and is subsequently more likely to fantasise and be positively aroused by the thought leading to more approach behaviours. Over time, these processes become strengthened and more automatic in both populations.

It is suggested that the cognitive operations that occur in response to intrusive sexual thoughts, happen on a secondary mechanism that is universal to all populations. This takes place once the thought has been appraised at a primary level. The function of these cognitive operations is thus to attempt to neutralise the distress or threat caused by the primary appraisal. As such, the secondary appraisal of those with OCD is more focussed on reduction of threat via thought suppression, reassurance seeking and compulsions. In OCD, the secondary appraisal also operates on an ego-dystonic evaluation. In contrast, sex offender's secondary appraisal is focussed more on the consequences of the thought. Thus they experience negative self-appraisals, worries and ruminations about getting caught. At this stage, sex offender's process the thought as ego-dystonic and therefore try to conceal it, rationalise it and justify it. It is argued here that previous research has failed to separate these primary and secondary elements of this cognitive process. As such, it is proposed that the appraisal process is more idiosyncratic to the individual as opposed to a simple matter of ego-syntonicity.

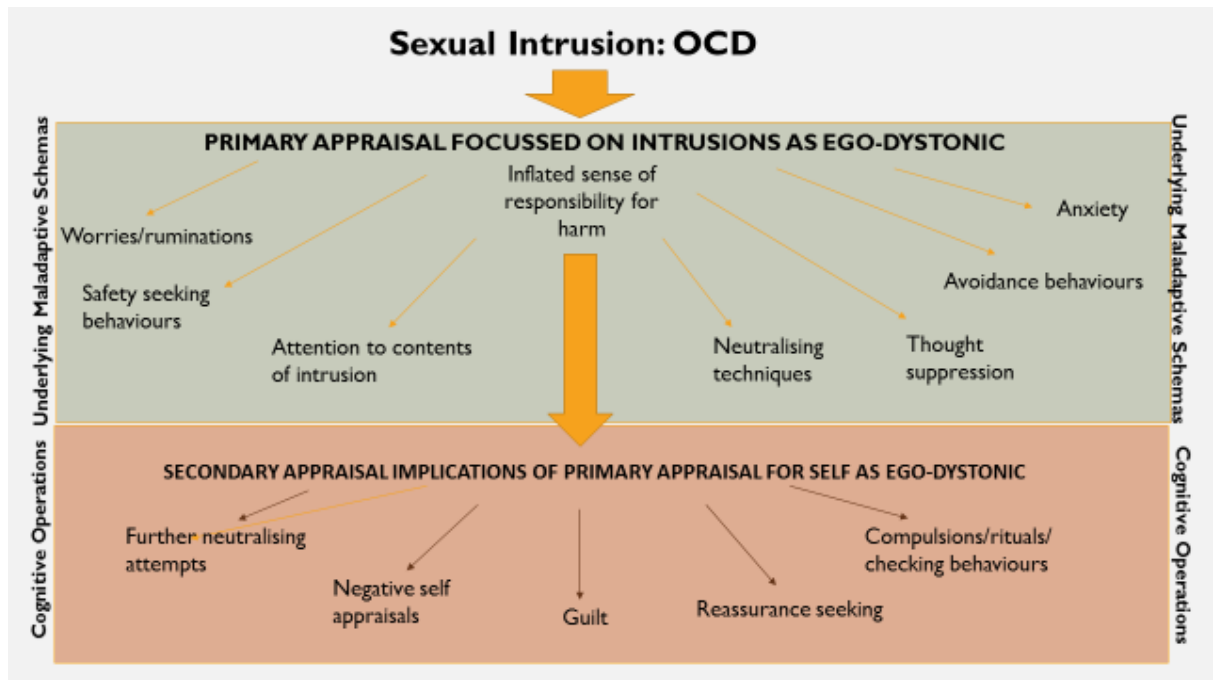


Figure 3: Proposed theoretical explanation for the cognitive processing of an intrusive sexual thought in someone with OCD

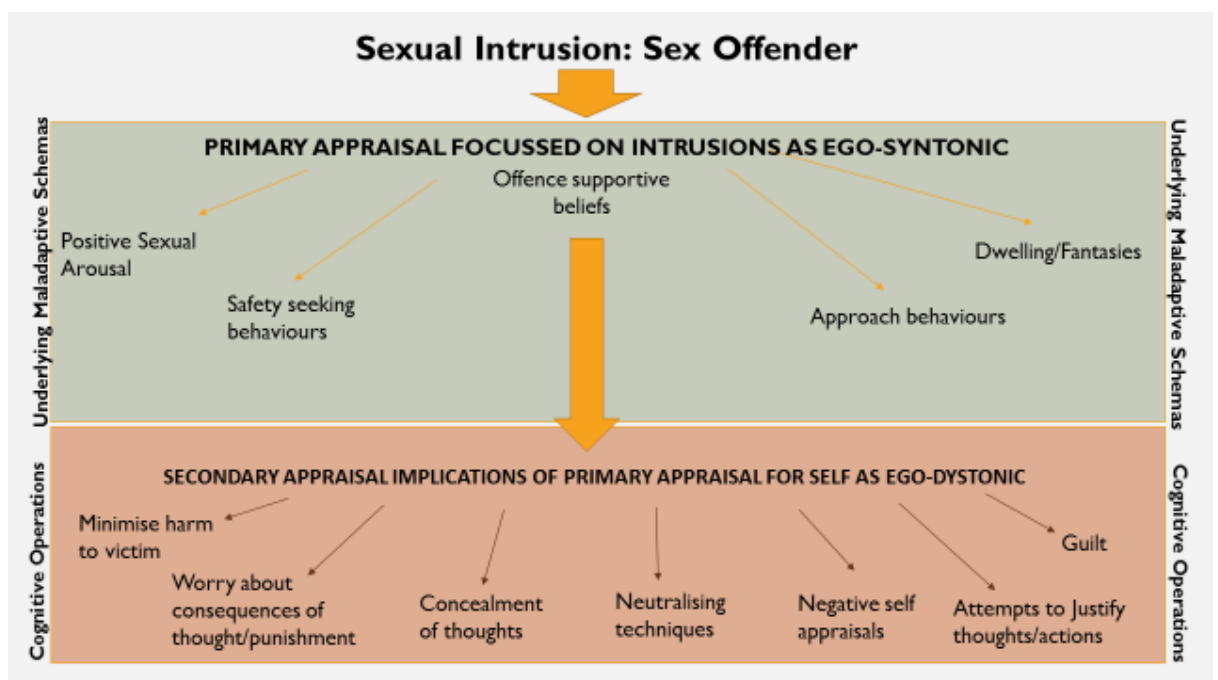


Figure 4: Proposed theoretical explanation for the cognitive processing of an intrusive sexual thought in a sex offender

It is suggested that the current theory goes some way to explaining why sexual offenders are able to act on thoughts despite them being ego-dystonic. Given that thoughts are appraised as ego-syntonic at a primary level, it was felt that this was a stronger motivator in facilitating

offending than secondary appraisals about consequences of thoughts. It is possible to hypothesise that some sex offenders' primary appraisals may be ego-dystonic, particularly in the early stages of their career, however the research evidence is anecdotal at this stage which makes drawing definitive conclusions difficult.

However, what is important to note is that the present theory acknowledges that the ego-syntonicity of thoughts may differ at varying stages of processing. Therefore, it is advised that the ego-syntonicity of thoughts are considered as part of a pattern of cognitive events. Given that current evidence emphasises the contextual nature of ego-syntonic appraisals, it is recommended that the theoretical explanation offered here to explain similarities and differences in phenomenology of intrusive sexual thoughts should be considered within a broader context. This supports Veale et al's (2009) conclusion that no single factor is sufficient to make a differential diagnosis of intrusive sexual thoughts, but that it is the overall pattern of differences is paramount.

Limitations

There were some limitations to the approach taken in the synthesis of information gathered for the current paper that are noteworthy. Given that the current paper was a narrative review of the literature, the selection and inclusion of studies were chosen at least partly subjectively illustrating a potential bias. Furthermore, due to the chosen methodology no in-depth evaluation of the quality of studies included was offered. No exclusion criteria were given on the basis of the quality of studies, and no quality assessment tool was used. As a result, this may limit the generalisability of the findings.

Clinical Implications

Whilst some distinct differences exist to support clinicians in making a differential diagnosis of intrusive sexual thoughts, there are some areas that remain unclear in the literature namely the influence of (i) sexual arousal and (2) checking behaviours. Firstly, the presence or absence of sexual arousal in response to deviant stimuli has been used to differentiate sex offenders. However, the current review has noted that sexual arousal in response to sexually deviant stimuli is apparent in both the general and clinical populations, whilst self-reported sexual arousal is prone to confusion and not considered an accurate indicator of sexual interest (Warwick and Salkovskis, 1990; Templeman and Stinnett, 1991; Veale et al., 2009).

Secondly, in general, it has been documented that a major difference between populations is the likelihood of acting on intrusive sexual thoughts. Existing literature argues that sex

offenders who find thoughts highly salient are more likely to act on thoughts and actively seek out the chance to do so (Smith and Waterman, 2004). On the contrary, individuals with OCD are so repulsed by their thoughts that it is doubtful they would act on thoughts (Gordon, 2002). However, it had been noted that occasionally people with OCD might act on their *compulsive* urge as form of checking behaviour (Veale et al., 2009). Current understanding of this behaviour is that it is driven by fear that one is responsible for harm coming to others. This anxiety subsequently motivates safety seeking behaviour in an effort to neutralise the discomfort experienced at having an ego-dystonic thought (Salkovskis, 1999). Therefore, existing evidence suggests that the motivation and intent behind these behaviours is qualitatively different across these populations.

The implications of the current findings clinically, are in support of Veale *et al's* (2009) notion that the assessment of intrusive sexual thoughts should be conducted by an experienced clinician who has a sound understanding of the phenomenology of these thoughts across different presentations. The current review has highlighted some significant qualitative similarities and differences in these presentations and clinicians need an awareness of these discrepancies in order to prevent misclassification.

Research Implications: Current drawbacks and future directions

Investigating the literature around intrusive sexual thoughts has highlighted a significant gap pertaining to sexual offenders. Two general observations are made: firstly, the literature has been plagued by an inherent need to separate sex offenders from the norm, and secondly, the lack of operational definitions in the sex offender literature has meant that the usefulness of any existing evidence on this issue has been sufficiently diluted.

In Group/Out Group Bias

The emphasis on differentiating sex offenders from the norm has reinforced the notion that sexual offending is resistant to change, and has been mirrored by the language used by researchers⁷ (Muller *et al.*, 2014). The main focus of research in this area has focussed on behaviour, which is perhaps understandable given that offending itself is a behavioural act. However, considering sexual offending solely in terms of behaviour can be problematic as it fails to address the complexities involved in the process and reinforces historical viewpoints

⁷ Terms like fantasy and addiction portray motivation, desire and intent, whilst sexually intrusive, ego-dystonic and perseverative indicate a disturbing and invasive experience.

that sex offending is entrenched and untreatable.

Lack of Operational Definitions

Whilst definitions of intrusive sexual thoughts have been inconsistent, the multiple terminologies used in the literature appear to be referring to the same phenomenon. Each suggests that sex offenders experience (i) persistent and intense thoughts that are (ii) highly consuming, (iii) that may be perceived as intrusive or excessive and (iv) difficult to control (Hanson and Harris, 2003; Fong, 2006; Marshall and Marshall, 2006; Kingston and Bradford, 2013). This draws parallels with diagnostic criteria for clinical obsessions (Clark, 2004). The current review has shown that sexual thoughts of sex offenders can also possess these qualities. Yet, to the knowledge of the author, the first and only mention of sexual thoughts of sex offenders meeting these criteria was put forward by Marshall and Langton over ten years ago.

Suggested Future Directions

The current review has illustrated the possibility that sex offenders experience cognitions that meet the criteria for intrusive thoughts. This therefore holds important implications for the assessment of intrusive sexual thoughts. It highlights the complexities in making a differential diagnosis with these cognitive phenomena. The author therefore advocates Veale *et al's* (2009) statement that assessment should be conducted by clinicians with an expertise in working with individuals with intrusive sexual thoughts. Evidence presented here suggests that using sexual arousal and ego-syntonicity as a measure of sexual interest are unreliable and should be done with caution. Alternatively, it is recommended that an increased focus should be placed on understanding individuals underlying offence supportive schemas and negative mood states.

Conclusions

In summary, existing research suggests that the cognitive processes involved in the onset and maintenance of intrusive sexual thoughts in sex offenders bears significant resemblance to that of the general and clinical populations. What is clear is that research in this area has been significantly hindered by preconceived research biases and a lack of clarity concerning operational definitions of terms. The proposed exploratory understanding of intrusive sexual thoughts in sex offenders presented here is based on a culmination of existing knowledge from two separate bodies of research. Consequently, further research is still needed to explore the cognitive process of intrusive sexual thoughts in the sex offender population.

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Service Improvement Project

Title: Identifying and addressing the needs of relatives in Critical Care Services at the Royal United Hospital, Bath.

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Candidate: Sarah Elliott

Hand-in-date: 25th July 2016

Academic Supervisor: Dr Catherine Butler

Field Supervisor: Dr Mike Osborn

Clinical Tutor: Lorna Hogg

Target journal: The Journal of Critical Care. It was considered that the current study would be consistent with the journal aims of improving patient care by integrating critical care systems knowledge into practice behavior.

Abstract

The aim of this project was to identify the needs of relatives in the Intensive Therapy Unit of the Royal United Hospital (RUH) in Bath. Existing evidence suggests that having a relative admitted to critical care can be stressful. In addition, relatives are often asked to take a more active role in the care given to inpatients during their stay. Therefore, it is increasingly important to recognise and meet the needs of relatives in the ITU department. Twenty-four relatives who accessed the ITU department of the RUH completed a questionnaire to help identify their needs and evaluate how well these needs were being addressed by the service. Findings indicated that to be given assurances about patient care was considered the most important for relatives, followed by clear, understandable information sharing. Identified needs are discussed in terms of potential areas of improvement for the service. Recommendations for how to implement suggested improvements are discussed.

Introduction

Critical care services are dedicated to the management and monitoring of patients with life threatening conditions and encompass intensive care units (ICUs), intensive therapy units (ITUs) and high-dependency care units (HDUs) (NICE, 2009). Over 100,000 patients are admitted to intensive care units in the UK each year (Griffiths *et al*, 2013). Critical care services in the Royal United Hospital (RUH) in Bath consist of eleven beds, with four (level 2) high dependency beds, and seven (level 3) intensive care beds as defined by the Intensive Care Society Document *Levels of Critical Care for Adult Patients* (2009). As a unit the RUH treats around 600 patients a year and have recently been commended by the Intensive Care National Audit and Research Centre (ICNARC) for their outstanding care, survival rates and cost-effectiveness (RUH Report, 2009). The unit consists of a large multi-disciplinary team that delivers family-centred care at level 2 and 3 critical care status.

Review of Current Literature: What are the needs of relatives in the ITU?

Traditionally the main role of family members in the ITU has involved passively awaiting information on their relatives' condition, with access to the critically ill patient being restricted to limited visiting hours (Garrouste-Orgeas *et al*, 2010). However, a growing body of research has helped promote the needs of family members and their function as active participants of the care process. The first of these conducted by Molter in 1979, led to the validation of the Critical Care Family Needs Inventory which has since been used and adapted internationally to help assess the needs of family members in critical care. Molter's pioneering work centred on the need to feel there is hope of recovery, that hospital personnel care about the patient and to be kept informed about the patient's progress (Molter, 1979). Since then research has categorised the needs of family members into roughly five domains including: (i) the needs for assurance, (ii) the need for proximity to critically ill relatives, (iii) the needs to be in comfortable surroundings, (iv) the need for support and (v) the need for honest information sharing (Leske, 1991; Lee and Lau, 2003; Auerbach *et al*, 2005; Chien *et al*, 2006; Miracle, 2006). Additionally, research has emphasised the importance of coming to terms with the shock of admission and the reality of critical illness in family members' experiences of ITU (Wilkinson, 1995).

The family-centred care model adopted by the RUH is a model aimed at helping address some of these needs. In Family Centred Care (FCC) the unit of care incorporates both the patient and their family rather than having the patient as the sole focus of care (Henneman and Cardin, 2002). Adopting such an approach aims to optimise outcomes through a shared process with families, patients and healthcare services that are based on the principles of mutual respect, collaboration and support (Hutchfield, 1999). This approach recognizes that the perspectives and information provided by patients and their families are important in clinical decision making. Given that a consensus is yet to be reached on the definition of

family centred care, the concept is often misunderstood as an 'ideal philosophy' of care that presents challenges for implementation in practice (Coyne *et al*, 2011; Kuo *et al*, 2012). While the RUH ITU department adopts this ethos towards the care they provide, they currently have no system in place to help them identify and address the needs of relatives, over and above those that fall under the remit of their duties of providing general medical care.

Why is it important to consider the needs of relatives in ITU?

Whilst there is now a clear understanding about the needs of family members in intensive care, little remains known about whether these needs are being met, and the psychological impact (both short and long term) of family members who have been through this experience.

Although many relatives regard their own needs as secondary to those of their critically ill relative (Verhaeghe *et al*, 2005), family members are becoming an increasing part of care giving for critically ill patients. Family members are now beginning to be recognised as legitimate recipients of critical care, often playing an important role in promoting the psychological well-being of the critically ill patient through their familiar and caring presence and meaningful interaction with the patient (Burr, 1998; Crunden, 2010). Many provide informal care during ITU stays, act as surrogate decision makers or advocates, collaborating with the treatment team in planning care, or administer formal care post discharge (Burr, 1998; Emanuel *et al*, 1999; Navaie-Waliser *et al*, 2002; Rabow, Hauser and Adams, 2004; Szalados, 2007).

Despite this, a family's ability to support the patient may become compromised by their own psychological distress, which in turn may have a negative impact on the patient's recovery (Maddox *et al*, 2001). The strain of having a relative admitted to ITU can create a stress response, increasing irritability, diminished attentiveness, feelings of helplessness and

depression (Ulrich, 1992; Hughes *et al*, 2005; Day *et al*, 2013). It is widely acknowledged that this is a distressing and 'unique' experience that relatives 'live' through, while the patient conventionally has little recall of the event (Daley, 1984; Plowright, 1995; Kleinpell, 2006; Paul and Rattray, 2008). Traditionally health professionals have been trained to focus on the needs of the patient, meaning that the needs of the family are often overlooked (Day *et al*, 2013). Research has suggested that if relatives' basic needs remain unmet, it impedes their ability to concentrate on the responsibilities that are required of them (Skelskey *et al*, 2005). Existing research suggests that relatives can experience symptoms of anxiety, depression, Post-Traumatic Stress Disorder and can suffer from severe sleep disturbance and fatigue (Rodriguez and San Gregorio, 2005; Day *et al*, 2013), suffered in both the short or longer term (Jones *et al*, 2004; Azoulay *et al*, 2005).

The uncertainty surrounding the ITU experience may also increase the psychological distress of relatives causing them to ruminate, catastrophize and worry about potential outcomes (Galfin and Watkins, 2012). When a loved one is admitted to the ITU, relatives are not only placed under extreme psychological pressure, but may also have to adapt to an unfamiliar and uncertain environment whilst accommodating major changes in their social and economic lives (Agard and Harder, 2007). Uncertainty over illness can be defined as 'a cognitive stressor, a sense of loss of control, and a perceptual state of doubt that changes over time' (Johnson Wright *et al*, 2009: 133). It can be argued that uncertainty can be experienced as more salient when presented with life-threatening situations such as an intensive care admission (Johnson Wright *et al*, 2009). Intolerance of uncertainty can be defined as a cognitive bias that effects how one perceives, responds and interprets uncertain situations, and could be considered a means to understand variability in relatives' responses to the critical care environment (Dugas *et al*, 2005). In essence intolerance of uncertainty means that uncertain situations are experienced as stressful and distressing, often leading to an inability to act (Dugas *et al*, 2005). Essentially it is the 'not knowing' about the outcome

of the potential threat (i.e. the prognosis outcome) that triggers excessive worry (Birrell, Meares, Wilkinson, and Freeston, 2011).

Current policy guidelines state that information concerning treatment and rehabilitation plans for patients in critical care should be discussed with the patient and their relative where appropriate in a format that is suitable and clearly understandable (Intensive Care Society, 2013; NICE, 2009). This is an ethos that is mirrored by the RUH's admissions and discharge policy (2010) which states that patients and relatives should be consulted about all aspects of critical care services, including withdrawing care, patient transfers and discharge. Whilst an appreciation of the role of relatives and the potential impact of an ITU stay on the family unit has been acknowledged in official guidelines, currently there are no regulations to support services in addressing the needs of relatives. According to the Core Standards for ICU's (Intensive Care Society, 2013) all critical care units should have a clinical coordinator available on the ward that is visible and accessible to staff, patients and relatives. The need for an increased focus on providing pastoral care and psychological support to patients and relatives in critical care services has also been mirrored by the Department of Health in their report 'Comprehensive Critical Care: A review of adult critical care services' (2000).

Aims and Objectives

The aim of the current project was to identify the most and least important needs of relatives in the RUH ITU department. Secondly, it aimed to evaluate the extent to which the most important needs recognised by relatives were being met by the service and identify any potential areas of improvement in regards to addressing needs suggested by relatives themselves. It was hoped that the findings and subsequent recommendations made from this research would support effectively reflect the ethos of family-centred care promoted by the RUH.

Questions to be addressed:

- 1) What are the most and least important needs of relatives in the ITU department of the RUH?
- 2) Of those needs identified as most important, to what extent are these needs currently being met well by the service?
- 3) What suggestions would relatives make about how to improve the service to successfully address their needs?

Methodology: Design and Data Collection

For the purpose of this research a relative or family member is defined as an individual who visited the patient on the ITU and had a sustained direct relationship with the patient. The research adopted a cross-sectional approach within a questionnaire design. The questionnaire was divided into two sections. Section one included the Critical Care Family Needs Inventory (CCFNI) developed by Molter in 1979 and adapted by Leske in 1986. The CCFNI contains a list of 45 need statements that aim to assess and report self-perceived needs of families in an ICU. Respondents are asked to identify how important each need is on a 4-point rating scale, ranging from 1 (not important) to 4 (very important). Leske (1991) organised the 45 needs of the CCFNI into five overarching themes. They are as follows:

1. Assurance: This refers to the need to be guaranteed that the best possible care is being given. Questions under this theme include ensuring aspects of communication with relatives are perceived as genuine and instil hope.

2. Information: This refers to a families need to understand what and why medical procedures are being carried out on critically ill relatives. This also includes knowledge about the physical status of patient, aspects of the environment and the roles of different staff

members.

3. Proximity: This refers to the need to be physically close to the patient. Questions under this theme include the frequency and availability of visiting, as well as maintaining communications with the family when they are not at the bedside.

4. Comfort: This refers to the need for the relatives waiting room to be considered comfortable and suitably equipped. This includes access to washroom facilities, comfortable furniture and access to consumables.

5. Support: This refers to the need to be emotionally supported by the service as well as being told of other services that may perform this function. Providing support may involve instructing relatives about what to do at the bedside, to talk about the possibility of death, to be alone and to be encouraged to cry.

The second section of the questionnaire was designed to measure how effectively the RUH is currently meeting the needs of relatives. Respondents were asked to identify their top five needs from the CCFNI and indicate on a 5-point rating scale, ranging from “not at all” to “very well” how well they felt that need was currently being addressed. A dialogue box at the end of the questionnaire was included to encourage respondents to make suggestions about how the service could improve in meeting their recognised needs. A copy of the questionnaires used can be found in appendix 3. Demographic data was collected on the relative and the admitted patient: information on the patient included their age, whether their admission was planned, if they had any previous ITU stays and the length of time of the current admission; relatives were asked their relationship with the patient and how far they travelled to the ITU (a copy of the information sheet, demographic information and consent form can be found in appendix 2).

It was hoped that enabling relatives to complete questionnaires in situ would maximise the

accuracy of the results obtained, therefore copies were made available to families in the ITU waiting room. Data collection ran over a 5-month period from September 2015 to January 2016. During this time 24 completed questionnaires were returned resulting in a 40% response rate from those left in the waiting room.

Data Analysis

Analysis of data took place in three stages, namely;

1. Descriptive analysis of Demographic Information

2. Descriptive analysis of relative's needs

Firstly, the mode or frequency for each of the 45 need items ranked as "very important" were collated and calculated as a percentage of the total sample. Additionally, mean responses for each theme were calculated by totalling the average response for each item within that theme. In effect providing an average mean score for each of the recognised themes.

3. Thematic Analysis of Qualitative Data

Respondents provided suggestions of how the service could improve how they dealt with recognised needs via the use of an open-ended dialogue box. An inductive thematic analysis was used to analyse the data using Braun and Clarke's (2006) six step guide. The rationale for undertaking inductive thematic analysis was to ensure the themes identified were strongly associated with the data gathered (Patton, 1990). A process of coding was completed to identify any recurring patterns in semantic or latent content. Codes were then organised into meaningful groups or themes (Tuckett, 2005). The analysis identified four themes from the qualitative data improving communication, access to patient and services, facilities, consumables and parking.

Results

1. Descriptive Analysis of Demographic Information: Relatives and Patients

Table one below illustrates the demographic characteristics of relatives and patients that accessed ITU during the research.

Table 1: Demographic characteristics of relatives and patients

Demographic data	Frequency	Percentage
<u>Age of ITU patients admitted⁸</u>		
Under 50 years	0	0
51 – 60	1	4%
61 – 70	14	58%
71 +	9	38%
<u>Type of admission to ITU</u>		
Planned	0	0
Unplanned	24	100%
<u>Previous experience of ITU admissions</u>		
Yes	24	100%
No	0	0
<u>Average length of stay in ITU⁹</u>		
24 hours	6	25%
2 - 6 days	11	46%

⁸ Average age of ITU patient was 69 years, with an age range between 54 and 85 years

⁹ Average length of admission to ITU was 9.3 days. Admissions ranged from 24 hours to 38 days.

7 – 10 days	2	8%
11 – 20 days	1	4%
20 – 31 days	0	0
Over 32 days	4	17%
<u>Relationship to ITU patient</u>		
Child	9	38%
Sibling	4	17%
Parent	4	17%
Spouse	2	8%
Extended family	4	17%
Friend	0	0
Other	1	4%
<u>Distance from hospital</u>		
Less than a mile	7	29%
Up to 5 miles	1	4%
Up to 10 miles	13	54%
Over 10 miles	3	13%

2. Descriptive analysis of relative's needs

Relatives Needs by Theme

Table two below outlines the lowest and highest mean scores obtained for each of the five themes identified by Leske (1991). The themes have been ranked according to the highest

total mean score achieved. Due to the fact that highest mean scores for proximity and information were the same, the lowest mean score was used to differentiate scores for ranking purposes.

Table 2: Lowest and highest mean need scores according to theme

Theme	Lowest Mean Score	Highest Mean Score	Ranking
Assurance	3.5	4	1
Information	2.6	3.8	2
Proximity	2.5	3.8	3
Comfort	2.7	3.6	4
Support	1.7	3.3	5

Relatives Needs Identified as Very Important

Table three below illustrates the top five needs rated by relatives as “very important”. See appendix 4 for summary of all 45 needs assessed and the frequency, percentage and ranking of responses of “very important” provided by relatives.

Table 3: The top five needs rated by relatives as “very important” by theme

Ranking	Most Important Needs	Percentage	Theme
1.	To have questions answered honestly	100%	Assurance
2.	To feel that hospital personnel care about the patient	96%	Assurance
3.	To be assured that the best possible care is being given	92%	Assurance
4.	To be given explanations that were understandable	92%	Assurance
5.	To know the prognosis of the patient	92%	Assurance

As is visible from table three above, all of the top five needs identified by respondents as “very important” fell under the theme of assurance.

Relatives Needs Identified as Least Important

Table four below illustrates the bottom five needs rated by relatives as “Not important”.

Table 4: The bottom five needs rated by relatives as “not important” by theme

Least Important Needs	Percentage	Theme
To have the pastor visit	50%	Support
To be informed of chaplain services	42%	Support
To be encouraged to cry	38%	Support
To have a telephone near the waiting room	29%	Comfort
To have someone to help with financial problems	25%	Support

As is notable from table four above, four out of the five least important needs identified by respondents corresponded with the theme of support, whilst one of the least important needs identified related to the theme of comfort.

Evaluation of how the ITU is meeting Relatives Most Important Needs

Table five highlights the top five needs identified by relatives, and their corresponding assessment of whether needs are currently being met well. It is important to note that none of the twenty-four relatives that completed the survey indicated their level of satisfaction with understandable explanations and to know the prognosis of the patient, despite them being identified in the top five needs. It was assumed that the reasons for this discrepancy were as a consequence of methodological issues that are discussed in the limitations. Needs were identified as met well, if they were recognised by more than two respondents.

Table 5: The top five needs rated by relatives as “very important” and the percentage of respondents who recognised these needs as being met “very well”.

Ranking	Most Important Needs	Very well
1.	To have questions answered honestly	25%
2.	To feel that hospital personnel care about the patient	12.5%
3.	To be assured that the best possible care is being given	12.5%
4.	To be given explanations that were understandable	Not rated
5.	To know the prognosis of the patient	Not rated

3. Thematic Analysis of Qualitative Data: Evaluation of Relatives suggestions to improve the management of their needs

Table six below outlines the identified themes and some example responses given by respondents.

Table 6: Respondent suggestions of ways to improve management of relatives' needs

Theme	Example Responses
Communication	<ol style="list-style-type: none"> 1. To respond to patients needs less dismissively/more compassionately 2. Sometimes Dr says an awful lot without saying anything 3. More frequent updates (on patient care)
Access (to patient and services)	<ol style="list-style-type: none"> 1. Dr is not always available for several hours 2. ITU is very busy 3. Phone/intercom in the waiting area to contact nurses 4. Flexible visiting times
Facilities	<ol style="list-style-type: none"> 1. Drink, toilet and TV facilities were out of order 2. A small kitchen space with kettle, toaster, microwave, fridge would be very useful for family to bring their own stuff to make drinks/snacks 3. Uncomfortable low chairs not good for elderly 4. More for children to do/need board games in the waiting area 5. Wifi access 6. Waiting room too clinical and bright

	7. Comfortable showers, varied seating and resting/sleeping areas
Consumables	<ol style="list-style-type: none"> 1. The family area needs a supply of tea and coffee and fresh milk 2. Passes for cheaper food (spent a lot on these) 3. Discount on food and drink 4. Access to food and drink earlier in the day
Parking	<ol style="list-style-type: none"> 1. When travelling 130 miles each way to visit next of kin it can take 45 minutes to find a parking space. 2. The cost of parking is expensive....it is not practical to use park and ride in these circumstances. 3. Parking facilities are very poor, there needs to be more free parking and an area specific for this 4. Passes for cheaper/free or priority parking

Discussion

Previous research has revealed that providing information and reassurance are frequently ranked within the most important need category for relatives in ITU (Lee and Lau, 2003). The current findings are consistent with this evaluation, with the theme of assurance being identified as the most important to relatives, followed by information.

According to Leske (1991) assurances are needed in order for families to construct a realistic

appraisal of the situation. Additionally, assurances provide families with hope, reduce uncertainty and stress, and help avert potential crisis (Mishel and Braden, 1988; Coulter, 1989). Within the theme of assurance, the need to have questions answered honestly was documented as very important by 100% of respondents. The mean score for this question was actually higher than Leske's original findings (4 in the current sample, and 3.92 in Leske's work). In addition, evidence gathered from the current research indicated that all three needs relatives evaluated as being met well at the RUH corresponded to the theme of assurance.

Existing evidence has indicated that having access to clear, understandable, and honest information about the patients' medical condition is important to relatives (Bernstein, 1990; Daley, 1984; Kleinpell and Powers, 1992). Furthermore, Auerbach and colleagues (2005: 202) noted that 'the manner in which this information is transmitted and the development of trusting and mutually respectful relationships between the family members and the healthcare team are crucial factors in helping families adjust to this traumatic situation'. Within the theme of information, the top need identified was to know exactly what is being done for the patient (mean score of 3.8) which was identified by 83% of respondents as very important. This finding is consistent with existing literature (Lee and Lau, 2003). Research has also noted that relatives' needs may fluctuate at different points during their contact with the service. Specifically, it has been reported that providing detailed information may be particularly beneficial during the initial stages of admission (Auerbach *et al.*, 2005). It is therefore important to note that the current research was cross sectional in nature, and therefore did not take into account any variations in the ITU admissions pathway. Conflicting evidence has been documented around the theme of information, with some literature indicating its increased significance (Daley, 1984; Coulter, 1989; Auerbach *et al.*, 2005), whilst others have minimised its importance to relatives' experiences (Leske, 1991; Lee and Lau, 2003). Wong (1995) suggested that variations in relatives rated needs can be attributed to

differences in critical care settings and subjects' cultural background.

Furthermore, it has been documented previously that when relatives are more concerned with the patient's condition as opposed to their own needs, the need for support is reduced (Azoulay, 2001; Lee and Lay, 2003; Hashima and Hussin, 2012). Within the current sample, support was recognised as the least important need by relatives, perhaps because in the current sample all the ITU admissions were unplanned. Previous research has highlighted that having a relative suddenly hospitalised can be ambiguous, unfamiliar and distressing (Auerbach *et al.*, 2005; Birrell, Meares, Wilkinson, and Freeston, 2011). It is noteworthy that none of the relatives in the present study had previous experiences with the service. Whilst no measure of psychological stress was given to relatives in the current study, it can be presumed that unexpected exposure to an unfamiliar clinical environment may have resulted in some distress. Consistent with Verhaeghe *et al.*'s (2005) report it is therefore possible that relatives considered their own needs as secondary to their critically ill relative and thus did not recognise support as significant. It is therefore important that critical care staff are aware of the consequences of an ITU admission on relatives.

Interestingly, although the overall theme of comfort was not considered important to relatives in the current sample, the majority of suggestions regarding improvements to the service related to the lack of comfortable surroundings. According to Arneill and Devlin (2002) having an appropriately equipped waiting room can increase one's satisfaction with the perceived quality of care given. Therefore, it is possible that providing a well presented waiting area may impact on relatives' satisfaction with care provided as well as increasing their levels of comfort. In particular, feedback from relatives centred on providing comfortable furniture, sleeping and washroom facilities in the waiting area and improving the quality and access to consumables in terms of food and drink.

Conclusion

In summary, whilst the current data is limited in scope by its small sample size, it is useful in terms of allocation of resources for critical care staff to be aware of the needs of relatives that are considered less important. Feedback suggests that continuing to provide adequate assurances and enhancing the physical comfort of the ITU environment may be more beneficial to relatives than investing resources in providing additional support needs (such as religious/spiritual or financial needs).

Limitations

A potential methodological issue was uncovered in the current project. Discrepancies were noted between the questionnaire and qualitative data. In other words, relatives did not consistently respond to the questionnaire as instructed. It was presumed that the reason for this was that the instructions provided were not clear, or that they were easily misunderstood. It is possible that creating the questionnaire collaboratively with a person with personal experience of ITU or piloting the tool may have identified this issue beforehand. Alternatively, it may have been useful to create an idiosyncratic tool specifically tailored to the service which allowed relatives to rate the importance of a need and also evaluate how well it was being addressed simultaneously. This may also have helped address some of the issues that were raised by utilising an older tool to measure relative's needs. Whilst the CCFNI has been extensively used in international research on this issue, it is possible that the tool may be less relevant to the modern day ITU and the relatives that use it. It can be presumed that the needs and expectations of relatives may have altered in the last 40 years since the invention of the CCFNI. It is possible that this had an impact on the findings of the current project. It may therefore be appropriate for the inventory to be updated to accommodate for this.

If the study were to be repeated asking respondents to complete the assessments at different time points during their relative's care pathway may have provided further information on whether needs fluctuate during admission. It is important to note that the current procedure was reliant on through put for the unit, which fluctuates depending on the number of admission and length of stay of patients. It was felt that extending the length of data collection, obtaining access to discharged relatives and using postal surveys may have boosted recruitment further.

Recommendations

- (1) Staff to receive training around improving communication with relatives on an annual basis in order to maintain the high standard and continue to develop skills in this area. It is advised that this training is considered part of the staff teams Continued Professional Development.
- (2) To introduce Patient Care Reviews on the unit. This involves staff setting aside a specified time to communicate with relatives on a daily basis or when there has been a significant change in the patient's medical condition. It is important that the format of these reviews ensures information provided is clear, understandable, and honest. It is advised that a record of these Care Reviews is kept in patient files and a copy provided to relatives to aid retention.
- (3) Improvements should be made in the physical environment and facilities available to relatives on the unit. In particular:
 - a. Improvements should be made to the presentation of the waiting room in an effort to make it appear more comfortable and less clinical. There is a specific requirement to provide comfortable and appropriate furniture.
 - b. Providing overnight facilities for relatives who incur an extended stay in ITU. This includes providing sleeping quarters and adequate washroom/shower

facilities

c. Access to communal resources should be provided including a fridge, microwave, kettle and TV.

d. Special dispensation to be given to relatives for parking facilities at the ITU.

This could include specified parking spaces, introduction of a permit system or a reduced rate for ITU users.

(4) An audit of these recommendations' is carried out within the first 6 months of implementation in order to evaluate progress.

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Main Research Project 1

Title: How do caregivers of children with co-morbid deafness and mental health difficulties experience and cope with their child's conditions?

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Hand-in-date: 25th July 2016

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Target journal: Journal of Deaf studies and Deaf education. The journal has published research pertaining to parental stress in response to a child's Deafness previously.

Abstract

Existing research indicates that caring for a child with additional difficulties can be challenging and stressful for caregivers (Mendenhall and Mount, 2011). Mental health problems and deafness can both be considered additional difficulties. However less is known about the impact this co-morbid presentation in children on their caregivers. The present study explored how caregivers of children with co-morbid deafness and mental health difficulties experienced and coped with their child's conditions. The project took place in two stages. The first stage was designed to measure stress, coping and adjustment in caregivers of deaf and non-deaf children with mental health difficulties. The second stage provided some contextual background to caregiver's experiences of rearing a child with co-morbid deafness and mental health difficulties.

Literature Review

It has been suggested that deafness itself does not cause mental health problems (Marschark, Lang and Albertini, 2002). However, a high percentage¹⁰ of deaf children experience co-morbid mental health difficulties (Department of Health, 2005). Current understanding of this relationship is that the absence of an auditory sense impacts the social and neurological development of sufferers causing an increased susceptibility to psychiatric disorders (Ohre, von Tetzchner and Falkum, 2011). Consequently, deaf children are placed at an emotional and behavioural disadvantage that gives them a greater risk for psychosocial maladjustment than hearing children (Yoshinga-Itano, 1998; Wallis, Musselman and MacKay, 2004; Wallis *et al*, 2004; Van Gent *et al*, 2007). Left untreated these mental health problems may continue into adulthood (Wright, 2011). There is little evidence exploring the impact of the specific co-morbidities of childhood deafness and mental health difficulties on caregivers. However, much has been written about the effect of a child's difficulties on their caregivers more generally, which we shall now outline.

¹⁰ Around 40 per cent of deaf children experience mental health difficulties compared to 25 per cent of their hearing peers.

Impact of Child Deafness and Mental Health Difficulties on Parental Stress

The majority of research into the impact of deafness on the family unit focusses on the interaction between deafness and child development. However, there is a growing body of literature addressing the increased stress placed on parents of deaf or hard of hearing children. Raising a deaf child can be challenging as parents are confronted with learning new communication methods, adopting technological support, making decisions about appropriate education and having increased exposure to professional services (Sanford et al, 1990; Calderon and Greenberg, 1999). This can often leave parents feeling helpless and deskilled (Kentish, 2007). This is further exacerbated by having a child who is considered different and who may communicate in a different manner to the rest of the family (Calderon and Greenberg, 1999). However, the ability of the child to effectively communicate via signing has been documented as having a significant effect on the level of stress experienced by caregivers. Evidence suggests that caregivers whose child signs fluently experience significantly less stress than parents whose child is unable to sign (Mapp and Hudson, 1997). It has been reported that over 90 per cent of deaf children are born to hearing parents (Moore, 2001).

Research suggests that parents of deaf children report more context-specific stress in relation to their child's deafness with major stressors including; communication difficulties, language delays, concerns about the future and child behaviour problems (Lederberg and Golbach, 2002; Quittner *et al*, 2010). Research also suggests that higher parental education, social support, high self-esteem and early identification of deafness can act as buffers to protect parents from stress (Meadow-Orlans, 1994; Konstantareas and Lampropoulou, 1995; Calderon and Greenberg, 1999).

For parents of children with mental health problems, the added symptomatology and impairment experienced by their children can magnify the stress and strain experienced (Taylor-Richardson, Heflinger, and Brown, 2006). According to Angold *et al*. (1998) approximately 10.7 per cent of parents feel burdened as a result of the psychiatric symptoms experienced by their child. The authors noted that the

complexity of child's presentation and level of impairment predicted perceived parental burden (Angold *et al.*, 1998). Evidence suggests that this burden can encompass all aspects of parent's lives including having financial implications, interruption at work, mental and physical health, and social and family relationships (Mendenhall and Mount, 2011).

So, we can assume from existing evidence that a direct link exists between the complexities of a child's difficulties, and the subsequent stress experienced by caregivers. It therefore stands to reason that the dual-diagnosis of deafness and mental health difficulties in children will have an increased effect on caregivers. Given the increased burden placed on these caregivers, it is important to consider how they cope with these additional complexities.

Coping with a child's additional difficulties

Coping is considered a psychological process of appraisals and responses that help us regulate distress, manage the stressful event and maintain positive wellbeing (Folkman and Greer, 2000). In other words, how we appraise and interpret an event influences how we cope with it. According to Moores (1987) the importance of this appraisal process can be seen in the responses of parents to the diagnosis of a child's deafness. Evidence suggests that hearing parents are more likely to appraise their child's deafness as highly distressing in comparison to deaf parents who are generally more accepting of the condition (Moores, 2001). For example, Sanford *et al* (1990) suggest that in families who are familiar with deaf services and where a deaf culture already exists, and in which sign communication is already used, deafness may not be viewed as a handicap. In contrast, hearing parents may appraise interaction and communication difficulties with their child as a barrier and thus become distressed. The authors therefore suggest that the impact of deafness on family dynamics can be dependent upon the meaning attributed to it (Sanford *et al.*, 1990).

Successful coping allows us to regulate stressful emotions, and alter our relationship with the environment causing the distress (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Consequently, coping has been hypothesized to predict successful adjustment (Brown, King, Butow, Dunn, & Coates, 2000). Understanding

the factors that differentiate successful from maladaptive coping may therefore provide us with a better understanding of the adjustment process, specifically in regards to a caregivers' response to their child's hearing loss.

Active coping strategies are designed to change the nature of the stressor itself or how one thinks about it. They refer to the specific efforts (behavioural and psychological), that individuals employ to help them manage stressful events (Taylor, 1998). Distinctions have been made in the literature between emotion and problem focussed coping strategies (Folkman, 1992). Problem-focused coping involves applying cognitive and behavioural skills such as problem solving to modify or eliminate the stressful situation, by taking control and evaluating possible outcomes. In contrast, emotion-focused coping attempts to regulate emotional distress in order to validate and manage stressful feelings (Folkman & Lazarus, 1980; Lazarus and Folkman, 1984).

Evidence suggests that these two methods of coping are not mutually exclusive, with individuals able to utilise both methods to combat stressful events (Folkman & Lazarus, 1980). However, individuals are likely to favour one method over the other. The decision as to which strategy dominates can be determined, by personal style (e.g., some people cope more actively than others) and the type of stressful event. However, research evidence suggests that emotion-focused coping is less effective and more likely to be associated with psychological distress than is problem-focused coping (Sigmon, Stanton, & Snyder, 1995). Furthermore, some individuals choose to adopt passive or avoidant strategies such as alcohol use or withdrawal that prevent them from directly addressing stressful events. This form of coping, tends to be a psychological risk factor for adverse responses to stressful life events (Holahan & Moos, 1987).

To enable this coping process to take place, five kinds of resource can be utilized (Folkman *et al.*, 1979). Table seven below outlines five types of resources that can facilitate positive adaptation to a stressor (Calderon and Greenberg, 1999).

Table 7: Five types of coping resources

<u>Coping Resources Available to Caregivers</u>
1. Parental problem-solving skills
2. Social support networks
3. Utilitarian resources (i.e. income, education, and outside intervention and other professional services)
4. Individuals general and specific beliefs (i.e. attitudes towards stressor or religion)
5. Individuals' health, energy and morale.

Access to these resources is believed to facilitate positive adaptation and adjustment to the stressor. In addition, they reportedly can impact on one's level of physical and emotional well-being that is experienced both prior to and during the course of the stressor (Calderon and Greenberg, 1999). In the deaf literature, it has been noted that the appraisal of available coping resources can also be influenced by the hearing status and experience of parents. For example, Deaf parents are considered to have more experience coping with hearing loss and consequently have increased access to resources that help support their coping process (Feher-Prout, 1996).

In summary the coping process consists of firstly appraising the stressor, and the available resources that might assist coping (such as social support, financial aid). Once this has been completed, and the event has been evaluated as stressful, individuals can then proceed to selecting behaviours (active coping strategies) that will help regulate their emotions or solve the problem, or alternatively choose to adopt passive or avoidant strategies that prevent them from having to directly address the stressor at that moment in time. Existing literature has highlighted the importance of considering meaning making and appraisals of child's condition on the coping process. Furthermore, it has been noted that certain coping styles, as well as access to resources can predict successful adjustment to a stressor. We now move onto explore what existing evidence tells us about this adjustment process in caregivers of children with additional needs.

Adjusting to a child's difficulties

Adjustment has been defined as: "a response to a change in the environment that allows an organism to become more suitably adapted to that change" (Sharpe and Curran, 2006: 1154). Consequently, in the literature adjustment has been referred to both as a dynamic process to navigate (Sharpe and Curran, 2006), and a desired a destination (Brennan, 2001). Whether someone has successfully 'adjusted' to change is therefore measured via consideration of their psychological function (e.g. social functioning or quality of life).

Existing research has noted that successful family adjustment to a diagnosis of deafness in a child can have positive outcomes for the child's development (Bodner-Johnson, 1986; Watson, Hennggeler and Whelan, 1990). However, less emphasis has been placed on how successfully navigating this process of adjustment to deafness can impact on parents.

In this context, adjustment can be conceptualised as a process of grief whereby parents pass through the various stages of bereavement, in response to the loss of their 'perfect child' (Kampfe, 1989). It has been noted that this enables parents to distance themselves from their idealised notion of their child and experience feelings associated with loss (such as anger and denial). Applying this framework to parental adjustment to a child's deafness implies that it will eventually become resolved. Kurtzer-White and Luterman (2003) suggest that this grieving process continues for the parent throughout the lifespan of the child and is activated during periods of transition where a disparity exists between the idealised child and reality. The authors argue that conceptualising adjustment in this context is better described as "chronic sorrow" (Kurtzer-White and Luterman, 2003:234). Calderon and Greenberg (1999) whilst investigating maternal and child adjustment to hearing loss, found that mothers with a higher level of negative life stress demonstrated poorer adjustment to their child's hearing loss. Furthermore, it was documented that parenting a child with less severe hearing loss does not present mothers with the same stress-producing concerns and thus may predict better adjustment.

Furthermore, for parents, deafness can be regarded as a deviation from that which is considered normal. As such the adjustment process may focus more on management and recovery from deafness as a disability (Lane, 1992). Consequently, parents may have to gradually construct an acceptable account of their disabled child that accommodates any disruption to family systems, deviation from the norm, and loss of an idealised child to successfully adjust. Research has also suggested that some parents view the experience of their child's deafness positively (Kashyap, 1983; Widerstrom, 1986; Martin, George, O'Neal, and Daly, 1987). Martin (1987) reported that 90 per cent of parents "had accepted the child's hearing loss by the twelfth month after learning of the disability" (p. 30).

Literature on adjustment to childhood deafness in caregivers suggests that previous experience with the deaf culture may facilitate successful adaptation. Furthermore, caregiver's adjustment can be likened to a process of grief which potentially indicates that the passage of time is an important variable in moving towards acceptance.

Summary

Existing research indicates caring for a child with additional needs, in terms of both mental health problems (Taylor-Richardson, Heflinger, and Brown, 2006) and deafness (Calderon and Greenberg, 1999) increases the stress and strain placed on caregivers. Current literature suggests that deaf children are more likely to develop mental health problems than their hearing peers (Department of Health, 2005). However less is known about the impact of this co-morbid presentation on caregivers. Given that the severity of a child's difficulties and level of impairment have been noted as strong predictors of caregiver stress (Angold *et al.*, 1998; Calderon and Greenberg, 1999), it appears likely that the comorbidity of mental health difficulties and deafness in a child may result in higher levels of stress experienced by caregivers.

In addition, it has been noted that how we appraise stressful events influences how we cope (Folkman and Greer, 2000), which in turn predicts how successfully we adjust (Brown, King, Butow, Dunn, & Coates, 2000). Existing research denotes that families and individuals differ greatly in their level of adjustment to their child's

hearing loss as well as in the styles adopt to help them cope with this diagnosis (Calderon and Greenberg, 1999). Current literature suggests that hearing parents of deaf children utilise similar coping styles and gain access to comparable resources to aid their coping process as the normal population (Feher-Prout, 1996). For example, access to sufficient social support has been documented as having a buffering effect on maternal stress and thus positively correlated to maternal adjustment to child hearing loss (Calderon and Greenberg, 1999). However little is known about whether caregivers of deaf children utilise these processes to a greater or lesser degree than their counterparts, or indeed whether the presence of an additional co-morbidity (such as a mental health problem) influences this coping process.

Exploring the factors that differentiate successful from maladaptive coping should provide us with a better understanding of the adjustment process for caregivers of young people with co-morbid deafness and mental health difficulties. Thus, understanding what factors differentiate between those families that adjust well (to their child's co-morbid deafness and mental health difficulties), and those who do not, may have important implications for services that support caregivers of children with these specific co-morbidities.

Aims, objectives and central hypothesis/questions

The main aim of this project is to explore how caregivers of children with co-morbid deafness and mental health difficulties experience and cope with their child's conditions.

Specifically, the research aims to address the following hypotheses:

1. Caregivers of deaf children will experience higher levels of stress than caregivers of non-deaf children.
2. Coping style, co-morbidity of child difficulties and child age will have an impact on caregiver stress response
3. Due to the nature of their child's co-morbidities, CAMHS and NDCAMHS caregivers will differ in the style of coping they use?

4. Active coping strategies will be more likely to result in positive adjustment in caregivers
5. Caregivers that have adjusted more positively to their child's difficulties would report less overall stress.

Qualitative Research

The qualitative arm of the study will explore the following question:

1. What factors do caregivers of children referred to ND CAMHS report as impacting on their experience of stress?

Methodology

Participants

Caregivers of children with mental health difficulties were recruited from the Child and Adolescent Mental Health Service in Salisbury (CAMHS). The CAMHS services are a specialist team working with children up to the age of eighteen who have a diagnosed mental health problem.

Caregivers of deaf children were recruited from the National Deaf Child and Adolescent Mental Health Service (ND CAMHS). Currently there are four main regional National Deaf CAMHS teams in England and one in-patient psychiatric facility for deaf children (Sessa and Sutherland, 2013). For the purpose of the current study, the four regional sites were targeted for recruitment¹¹.

Design

The study was cross-sectional in design adopting a mixed methods approach. The main aim of the project was to explore how caregivers of children with co-morbid

¹¹ ND CAMHS provide specialised consultation, assessment, interventions and advice to deaf children and their families. The service integrates specific deaf cultural knowledge and in-depth knowledge of child mental health (Sessa and Sutherland, 2013). The service works with children and young people aged 0 - 18 who have a severe to profound hearing loss, have deaf parents or have BSL (British Sign Language) as a first language. Referrals can be made from professionals working with the child, young person and family. This includes schools, other CAMHS services or Child Services and GP's.

deafness and mental health difficulties experience and cope with their child's conditions.

The quantitative arm of the study was designed to measure stress, coping and adjustment in caregivers of deaf and non-deaf children with co-morbid mental health difficulties. Participants consisted of two groups of caregivers. Group one included caregivers of deaf or hard of hearing children recruited from specialist deaf CAMHS services (ND CAMHS). Group two contained caregivers of children referred to a generic CAMHS service. Participation in this phase of the project involved caregivers completing a battery of three questionnaires designed to measure their overall level of stress, coping strategies and adjustment to their child's difficulties. It was anticipated that this would take approximately 30 minutes to complete.

The qualitative arm of the study aimed to explore caregiver experiences of rearing a child with co-morbid deafness and mental health difficulties. Participants recruited from ND CAMHS services in stage one of the research were invited to take part in semi-structured interviews to gather more in-depth information about their experiences. Interviews took place on a one-to-one basis and lasted no longer than one hour¹².

Procedure

Caregivers were approached to take part in the study by their respective CAMHS/NDCAMHS clinicians who were fully briefed on the aims of the project. The project was also advertised in the waiting rooms of NDCAMHS and CAMHS clinics to promote participation. Caregivers were provided with an information pack containing details of the study, procedures, consent forms, dissemination plans and psychometric measures (outlined below). Demographic information was also collected for both the caregiver and child. A stamped addressed envelope was provided for caregivers to return all documents to the researcher. Caregivers were also given the opportunity to be contacted to arrange a suitable time for them to take part in the second interview phase of the project. Each parent or caregiver

¹² The study and subsequent amendment (see connecting narrative) were granted full ethical approval via the Integrated Research Approval System.

participated in the study independently in an effort to eliminate family dynamics as an extraneous variable.

Interviews were semi structured in nature with the aim of allowing caregivers to detail their experience of having a child with additional difficulties (i.e. mental health and/or deafness). Questions centred on asking caregivers to explore the impact of their child's difficulties on their levels of stress, whether they have any beliefs around their child's condition that may influence how they perceive it, and what they feel helps them to cope with these challenges.

Inclusion/Exclusion Criteria

Table eight and nine below illustrate the inclusion and exclusion criteria for the control group (CAMHS) and experimental group (NDCAMHS).

Table 8: Criteria for Control Group (CAMHS)

Inclusion Criteria	Exclusion Criteria
1. The caregiver of a young person accessing services including adoptive and foster parents	1. Caregiver unable to understand and complete questionnaire independently
2. The child had a diagnosable mental health difficulty	2. Paid carer of child
	3. Child hearing impairment
	4. Caregiver hearing impairment

Table 9: Criteria for Experimental Group (NDCAMHS)

Inclusion Criteria	Exclusion Criteria
1. The caregiver of a young person accessing the service including adoptive and foster parents	1. Caregiver unable to understand and complete questionnaire independently
2. The child had a diagnosable mental health difficulty	2. Paid carer of child
	3. Caregiver hearing impairment

Measures

The following standardised measures were used. Measures were chosen for their validity and use in existing literature.

1. Caregiver stress: The Paediatric Inventory for Parents (PIP)

The Paediatric Inventory for Parents (Streisand *et al.*, 2001) is a 42 item questionnaire that assesses parental stress in response to their child's illness. It measures the frequency and perceived difficulty of stressful (illness-related) events across four domains namely; communication, emotional distress, medical care, and role function. Frequency of each item is rated on a 5-point scale from never (1) to very often (5). Difficulty of each item is also rated on a 5-point scale from not at all (1) to extremely (5). Separate frequency and difficulty scores are obtained for each domain. In addition, domain scores are combined to produce a PIP Total Frequency, and PIP Total Difficulty score. The PIP has been documented as a reliable and valid tool for measuring parental stress in pediatric oncology populations (Streisand *et al.*, 2001).

2. Caregiver Coping

The Brief COPE scale (Carver, 1997) is a 28-item self-report scale that measures adaptive and maladaptive coping skills as well as emotion-focused and problem-focused coping styles. The Brief COPE investigates 14 domains of coping behaviours namely; self-distraction, active coping, denial, substance use, use of emotional

support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame. Each item is rated on a 4-point scale from not at all (1) to a lot (4). Whilst no overall coping index can be generated with this tool, individual variables scores can be viewed in relation to other variables. Additionally, second-order factors can be generated from the scales, using the factors as predictors (Carver, Scheier, and Weintraub, 1989).

3. Caregiver adjustment: The Parenting and Family Adjustment Scales (PAFAS)

The Parenting and Family Adjustment Scale was designed as a brief outcome measure for assessing changes in parenting practices and parental adjustment in the evaluation of both public health and individual or group parenting interventions. The scale consists of 28 items encompassing two domains including parenting practices (17 items) and parent–child relationship (11 items). Additionally, it includes a 12-item Family Adjustment scale encompassing three domains including parental emotional maladjustment (5 items), family relationships (4 items) and parental teamwork (3 items). Each item is rated on a 4-point scale from not true of me at all (0) to true of me very much (3). Items are summed to provide scores, with higher scores indicating higher levels of dysfunction. The PAFAS has been reported to have good internal consistency, as well as satisfactory construct and predictive validity (Sanders *et al.*, 2014).

Plan of Analysis

Quantitative: Standardised measures were analysed and scored according to the criteria for each test. The original strategy for analysis involved conducting linear multiple regression to establish if relationships existed between the way parents coped with and adjusted to their child’s deafness and their level of stress. Demographic characteristics of the child (e.g. age, other disability) and circumstances surrounding the diagnosis of deafness (e.g. length of time since diagnosis, type of deafness, previous contact with services) were also to be included in the regression.

Given the shortage of comparable studies in this area, *a priori* power calculation was used to estimate the required sample size. Previous research investigating the impact of child illness on parental stress has reported a large effect size (Darke and Goldberg,

1994; Mattie-Luksic, Javornisky and DiMario, 2000). Resultantly, a large effect size of 0.80 was entered into GPower using Cohen's D (Faul, Erdfelder, Buchner, and Lang, 2009). With significance level set as .05 and power at 0.80 a required sample of approximately 43 (in each group) was suggested. However, changes to the planned analysis were made in response to participant numbers. Non-parametric tests were adopted as the small sample size meant that the distribution would not be normal.

Qualitative: One-to-one semi structured interviews with parents were analysed using Interpretative Phenomenological Analysis (IPA). The primary goal of IPA is to investigate how individuals make sense of their experiences. (Smith, 2004). This method of analysis was chosen due to its consistency with the aims of the project. It was anticipated that the researcher would transcribe each interview individually in order to establish and document any emerging themes or consistent patterns in responses. Themes could then be grouped together according to conceptual similarities (Pietkiewicz and Smith, 2014).

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Connecting Narrative

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Candidate: Sarah Elliott

Hand-in-date: 25th July 2016

Clinical Tutor: Lorna Hogg

What has been presented here is two studies. The first, is an exploration of a child's co-morbid deafness and mental health difficulties on their caregivers. This project illustrates the trainee's ability to design, conduct and write up a research study, including being able to successfully navigate the process of obtaining ethical approval. The second, is a community focussing study investigating the types of information that are beneficial to encourage people to seek treatment for OCD. The purpose of this study was to demonstrate the trainee's ability to analyse and interpret data, coming to meaningful conclusions and making a contribution to the literature. What follows is an explanation of the research process in this case including the rationale behind the decision to terminate the first project and the selection of a new one.

The research proposal for the original project was submitted and passed by the University for appropriateness in August 2014. Given my lack of expertise in the field it took a while to familiarise myself with the literature and the logistics of conducting research in a minority culture. I was fortunate at this time that Dr Mary Griggs kindly consulted on the project. We held a few meetings to discuss the potential areas for research and how this would look in practice. Dr Griggs advised me getting in touch with Dr Maria Gascon-Ramos who was the service manager in NDCAMHS in Taunton. Dr Gascon-Ramos had extensive experience of conducting research in Deaf services and agreed to supervise the project. We discussed utilising Dr Gascon-Ramos's service as the main participant information site for the project and I began liaising with R&D for the trust at this point.

I began networking, by attending the annual Deaf CAMHS conference and various staff meetings with the main teams in an effort to promote the project. With the help of Dr Gascon-Ramos we managed to gain the agreement from three other services to host the research. Unfortunately, shortly after this Dr Gascon-Ramos went off on maternity leave and did not return during the project. I therefore made an effort to maintain contact with the services and identified a local collaborator in each one who agreed to oversee the research at their site.

The first application for ethical approval was applied for at the start of November 2015, which was initially rejected for a proportionate review. It was advised that a full ethical committee decision would be needed due to the complexities of the client group. Permission was granted by IRAS at the start of January 2016. Whilst approval from individual NHS R&D departments varied, all sites began collecting data by the end of February 2015.

Active collection continued for several weeks, with the researcher maintaining constant contact with the local collaborator in each location. At this stage, 175 packs were distributed between the five participant information sites. Unfortunately, only 2 completed pieces of data were received during this time period. Myself and my academic supervisors became concerned at this stage about the speed of recruitment. I discussed this with the individual local collaborators to gain their feedback. We established that approximately 41% per cent of the packs provided had been handed out. The consensus around this was that because we were asking them to hand out packs to caregivers only at initial assessment, this was restricting their numbers. Collaborators shared that the number of new referrals they received on a weekly basis was unpredictable which therefore made it difficult for them to predict whether or not recruitment would pick up. We therefore decided to apply for a substantial amendment to the project to respond to this feedback. At the time, although we had a clinical rationale for only targeting caregivers at initial assessment, on weight of balance we felt it was more appropriate to expand the inclusion criteria to caregivers on existing caseloads for the teams. The substantial amendment was applied for at the start of April 2016. Approval on this was received 2 weeks later and the amendment was communicated to all R&D departments and services quickly. A further 175 packs were then distributed across the sites and a second phase of recruitment began. Myself and my supervisors continued to monitor the situation closely. We also raised our concerns with the course director at this stage so that we could start considering alternative options should it become necessary. After 6 weeks of active data collection, we only obtained a further two completed packs (giving us 4 in total). Of these, one was received from Taunton, one from Salisbury and two from York.

Our concern about the recruitment difficulties was subsequently not alleviated. I went back to the services to enquire about what they felt may have been impacting on this process. Further discussion highlighted that approximately 38% per cent of the second packs provided had been handed out to potential participants. In general, it was suggested that the services themselves were stretched. A decrease in funding and increase in staff sickness meant that the teams were in a state of fluctuation, making it difficult to maintain the enthusiasm and drive for the project. Furthermore, one collaborator mentioned that she felt caregivers were too stressed to complete the questionnaire in her area. We consulted with the local collaborators about whether any additional amendments at this stage would be likely to increase numbers. We were advised that this was doubtful. After exploring the options with my course director, my supervisors and I made the difficult decision to terminate the project.

At this point (May, 2016) it was suggested that I take up a new piece of work. Discussing this with the course director, we noted that in order for me to demonstrate a completed piece of research, I needed to adopt a project that was already developed. I was fortunate that Karen Robinson had a research project that already had ethical approval granted, that she very kindly gave me permission to run with. I liaised with Karen over the project and got up to speed with the literature. A single amendment was required for the ethical approval to be gained, and this was fortunately accepted via a chair's action. This meant that I could start data collection quickly. I was assisted in this process by an Undergraduate psychology student which was extremely beneficial. Once all the materials were in place, we set about obtaining approval to recruit at a variety of different community venues. We eventually were able to utilise a supermarket car park, café on the University of Bath campus and a farmers' market. Uptake on the project was good and we were able to complete data collection in 3 weeks. The analysis and write up took a further 2 weeks to complete.¹³

¹³ Please see Narrative Overview of Research Portfolio on page 123 for reflections on this process.

Main Research Project 2

Title: Seeking help for OCD – A community focusing study

Word Count: 5226

Candidate: Sarah Elliott

Hand-in-date: 25th July 2016

Academic Supervisors: Professor Paul Salkovskis

Clinical Tutor: Lorna Hogg

Target journal: Behaviour Research and Therapy. The journal has published previous research on hypothetical help seeking, and OCD, so it was deemed an appropriate one to target.

Abstract

Background. Despite the potentially severe psychosocial impact of OCD and the its treatability, evidence suggests that people wait many years to seek treatment (Stobie, Taylor, Quigley, Ewing, and Salkovskis, 2007). The psychological processes involved in the decision to seek treatment for OCD have received surprisingly little research attention. It has been documented that a lack of information can act as a barrier to seeking treatment for OCD (Robinson, Rose and Salkovskis, in press). Research in other areas has indicated that decision making outcomes correspond with areas in which people are encouraged to focus on at the time of decision making (Wroe and Salkovskis, 2000; Wroe, Salkovskis and Rimes, 2000; Salkovskis, Rimes, Bolton and Wroe, 2010).

Objectives. The present study aimed to explore whether the type of information presented and focussed on by community controls (without OCD) influenced the likelihood that they would seek treatment if they developed OCD.

Design. An analogue study was conducted using people who were not suffering from OCD that were recruited in the community.

Methods. The seventy-five included participants were recruited through community settings to complete a focussing intervention. Participants were asked to rate how likely they would be to seek help for OCD before and after reading and rating for self-applicability, specific information designed to focus their attention either on previously identified “enabler” factors or on general information about OCD.

Results. Results indicated a significant shift in the likelihood of seeking treatment for OCD when participants were asked to focus on enabling information as opposed to more general information on OCD.

Conclusions. Providing people with any type of information about OCD is helpful in increasing the likelihood of hypothetically seeking help, however focussing on enabling factors is more facilitative in terms of adjusting people’s attitudes towards treatment seeking.

Introduction: What is Obsessive Compulsive Disorder (OCD)

Obsessive compulsive disorder (OCD) is an anxiety disorder categorised by the experience of obsessional intrusive thoughts accompanied by repetitive behavioural compulsions

(Diagnostic and Statistical Manual, 2013). OCD is a relatively common condition with current estimates placing it as the fourth most common psychiatric illness, with a lifetime prevalence of 1 to 3% (Ruscio, Stein, Chiu and Kessler, 2010). Despite its commonality, OCD can have a profoundly negative and disabling impact on people's lives and sufferers are frequently reluctant to seek help (Robinson, Rose and Salkovskis, in press).

Although historically OCD was considered treatment-resistant, over the last fifty years' effective psychological treatments have been developed and the condition is now considered treatable (Rachman and Hodgson, 1980; Salkovskis, 1999; Franklin and Foa, 2007). Despite the potentially severe psychosocial impact of OCD and its treatability, evidence from research conducted in the UK indicates that on average people wait six years after the OCD begins to significantly impact on their lives to seek treatment (Stobie, Taylor, Quigley, Ewing, and Salkovskis, 2007). This delay between OCD symptom onset and seeking help is a finding that has been widely documented in the UK and elsewhere (Pinto, Mancebo, Eisen, Pagano, and Rasmussen, 2006; Belloch, Del Valle, Morillo, Carrio, and Cabedo, 2009).

This delay in seeking treatment can and usually does have significant direct and indirect costs for the individual. Over time OCD symptoms can become chronic having a profound impact on individual's psychosocial functioning and quality of life. Symptoms can make it difficult for individuals to function in their day to day lives, thus impacting on their relationships and ability to work (Hollander *et al.*, 1996; García-Soriano *et al.*, 2014). Evidence suggests that the longer OCD is untreated, the worse treatment response is likely (Dell'Osso *et al.*, 2010; Eisen *et al.*, 2010). A variety of factors may act as barriers to individuals seeking treatment. Existing evidence indicates that the stigma associated with symptoms as well as a lack of awareness about OCD means that people don't realise the significance of their symptoms (Stengler-Wenzke and Angermeyer, 2005; Torres *et al.*, 2006; Marques *et al.*, 2010). Consequently, it is likely that only those whose OCD is most severe and disabling seek help (Goodwin, Koenen, Hellman, Guardino, and Struening, 2002).

Decisions to seek Treatment

The psychological processes involved in the decision to seek treatment for OCD have received surprisingly little research attention. However, some research has been conducted into decision making around seeking treatment for physical health conditions which may provide a framework to assist our understanding. One model that has been applied to this arena is the subjective expected utility theory originally proposed by von Neumann and Morgenstern (1947). The main assumption of this theory, developed in the context of

economics, is that “rational” decision making involves systematically evaluating and weighing up alternative choices in order to maximise positive outcomes. Thus when faced with decisions individuals act according to the balance of positive versus negative outcomes that are deemed relevant to them at the time of choice (Kahneman and Tversky, 1979; Wroe, Salkovskis and Rimes, 1998).

Wroe, Salkovskis and Rimes (1998) applied this theory to explore people’s decisions whether to undertake predictive testing for medical conditions. These authors suggested that whilst utility theory provides a useful conceptualisation for understanding decision making, it fails to explain why some people make decisions that are fundamentally unhelpful or inappropriate in the longer term, particularly in regards to their physical health. They proposed an elaboration to the original theory starting from the assumption that individuals appraise situations in ways that are consistent with the beliefs about that situation which are active at that time. Wroe *et al.* (1998) noted that the particular reasons behind decision making (and the probabilities and weights assigned to them) may be idiosyncratically determined according to the persons prevailing internal logic and focus at the time the decision is made. As such, the reasons influencing the decision include only those on which the decision maker focuses at the time. The authors noted that this is also likely to be influenced by emotional factors.

In the first of a series of studies Wroe, Salkovskis and Rimes (1998) investigated the analytic strategies for the understanding and modification of factors involved in the uptake of physical health screening. Wroe and colleagues investigated the likelihood of opting for predictive testing for a variety of health conditions and the reasons for this decision. Their findings supported the application of Modified Utility theory noting the importance of evaluating the positives and negatives of testing on decision making. Wroe *et al.* (1998) concluded that when reasons for and against a decision are weighted in terms of relevance or utility, they predict decision making. As such, decisions are influenced by a motivation to maximise perceived gains and minimise losses. If this is the case, then decision making can be considered an internally logical process that is based upon idiosyncratic reasoning. The authors noted that this decision although logical to the individual, may not appear rational to others (Wroe *et al.*, 1998). Since this time, a number of other research studies have provided support for this notion (Wroe and Salkovskis, 2000). In general, current understanding dictates that prior to considering whether or not to seek hypothetical screening for risk of physical disease (genetic or otherwise), the ratio of advantages versus disadvantages which the person is aware of at the time they are asked are key. Within the

medical arena patients are often provided with pre-emptive information about available treatments, the test available and potential side effects. Consultations are meant to be non-directive in nature allowing patients' autonomy in their decision making (Dailey, Pagnotto, Fontana-Bitton, and Brewster, 1995). Wroe and colleagues research had highlighted that the nature and focus of this exchange can bias the actual decision of the patient (Wroe *et al.*, 1998).

Research has noted that variations in decisions about whether or not to undergo health screening correlate with the information presented to an individual, even if understanding of the potential outcomes are the same (Wroe, Salkovskis and Rimes, 1998; Wroe, Salkovskis and Rimes, 2000). In particular, it has been reported that decision outcomes correspond with the areas in which individuals are encouraged to focus at the time of decision making (Wroe and Salkovskis, 2000; Wroe, Salkovskis and Rimes, 2000; Salkovskis, Rimes, Bolton and Wroe, 2010). For example, individuals who focus on positive aspects of screening or treatment are more likely to opt for treatment if offered. On the contrary, when individuals are encouraged to focus on negative aspects of an intervention, they are more likely to reject treatment. The nature and amount of information received by patients about medical options has also been associated with satisfaction and adherence (Wroe, Salkovskis, Rees and Jack, 2013). Furthermore, the rated likelihood of opting for testing generated from hypothetical decision making has been linked with the actual uptake of treatment (Wroe, Salkovskis and Rimes, 2000). Using Wroe and Salkovskis's (1998) Cognitively Modified Subjective Utility Theory to explain decision making therefore provides some explanation as to how decisions are made and how they might be influenced.

Given the documented influence of information provided on decisions whether to seek treatment for medical conditions, it is important to consider the barriers that prevent people seeking treatment for OCD. It has been widely acknowledged that a lack of information about OCD can act as a significant barrier to treatment seeking. Specifically, existing evidence suggests that a lack of awareness about the meaning and significance of OCD symptoms and its treatability prevent people from accessing appropriate services (Nestad, Samuels, Romanoski, Folstein, and McHugh, 1994; Fireman, Koran, Leventhal and Jacobson, 2001; Goodwin, Koenen, Hellman, Guardino, and Struening, 2002; Stengler-Wenzke and Angermeyer, 2005; Torres *et al.*, 2007; Belloch *et al.*, 2009; García-Soriano, Rufer, Delsignore and Weidt, 2014; Robinson, Rose and Salkovskis, in press).

Robinson, Rose and Salkovskis (in press) investigated factors which enable people to seek treatment for OCD and barriers to this help seeking in a qualitative study. The authors distinguished between positive enablers (factors that encourage people to seek treatment), and negative enablers (factors that drive people to seek treatment). Findings indicated that it was only when there was a sufficiently powerful negative enabler, such as reaching a crisis point, that participants felt forced to seek help. However, a small number of positive enablers were described including being supported by friends and family to seek help (Robinson *et al.*, in press). Given the acknowledged time delay in treatment seeking when individuals rely on negative enablers to drive them to seek treatment, it would make sense that attempting to maximise the positive enablers for patients would be more beneficial.

So, current evidence suggests that the type of information presented to individuals during the decision making process can influence whether or not they choose to seek treatment. Existing literature suggests this is the case for both physical health conditions and pre-screening for mental health problems such as schizophrenia. Therefore, it can be hypothesised that focussing on more positive factors to do with treatment option, such as the benefits, can encourage people to seek treatment. However, to date, research into the Cognitively Modified Subjective Utility Theory (Wroe *et al.*, 1998) has not investigated its role in psychological treatment seeking. The positive factors which are, *a priori*, most likely to encourage treatment seeking can be derived from the work on enablers identified as involved in the decision of those suffering from OCD to eventually seek treatment. We propose applying this novel decisional support approach to OCD, as an important exemplar of a mental health problem where delays in presentation for diagnosis and treatment are the rule rather than the exception. In order to gain a sense of whether the Cognitively Modified Utility Theory and our decision analytic strategies can be applied to OCD, we conducted an analogue study with members of the public who do not have OCD asking them to focus on and apply to themselves either general information or factors identified as treatment seeking enablers.

Research: Question

1. Does being provided with information about and focussing on enablers for treatment influence the likelihood that community participants without OCD would hypothetically seek treatment if they developed OCD relative to being provided with and focussing on general “psychoeducational” information about OCD?

Hypotheses

A priori hypothesis was generated predicting that when community volunteers (who do not have OCD) are provided with general psychoeducation type information on OCD with enhanced processing through focussing, this will not significantly increase their rated likelihood of seeking help were they to develop OCD. However, when provided with information known to enable help seeking with enhanced processing through focussing, this will significantly increase their rated likelihood of seeking help were they to develop OCD. We proposed the method would work by systematically drawing attention to and promoting the processing of already known enabling factors. A secondary prediction was made that the extent to which people rate enabling factors as relevant to themselves will related to the extent of any increase in the rated likelihood of seeking help.

Data collection

Sample and Inclusion Criteria

Community volunteers (who do not have a diagnosis of OCD) were approached in community settings such as supermarket car parks, cafes and market sites to complete the focussing intervention. Adults aged from 18 to 90 years who self-defined as not having OCD, and who had sufficient knowledge of English to be able to fully understand and complete the questions were included. Participants were excluded from taking part if they did not meet this criteria, or if they reported having an intellectual disability or other serious mental health problem. Additionally, if participants self-reported having OCD or were unsure, they were excluded from the study and were signposted to appropriate support services, in particular the OCD charity websites.

Methodology: Design

An analogue study was conducted using people who were not suffering from OCD that were recruited in the community. For the primary analysis, a repeated measures (2x2) approach was adopted with the experimental group acting as the between subjects variable and time point acting as the within subjects' variable. The independent variable (IV) was the type of information given and focussed on by participants. The dependent variables were the rated likelihood of seeking treatment for OCD (should one develop it) taken before and after the specific information was provided and focussed on. The four dependent variables (DV) corresponded to the four pre and post outcome questions participants were asked. The primary DV was identified as "likelihood of seeing GP to discuss treatment". The rationale

for this decision was because GP's are the first point of contact for individuals presenting with first episode mental health difficulties. The remaining dependent variables included; (i) rated likelihood of finding out more about CBT, (ii) likelihood of requesting CBT as a treatment, and (iii) likelihood of accepting at least 12 sessions of CBT.

Randomisation to experimental or control condition took place with the assistance of an online tool¹⁴, and sampling was completed without replacement. All participants received the same general information about OCD, they were randomised to receiving and focussing on by means of ratings, two different types of information. In condition 1 (controls) the information provided and focussed on concerned psychoeducation type material about OCD. This included the nature of the treatment and commonality. In condition 2 (enablers) information provided and focussed on was drawn from previous research on factors known to enable treatment seeking. This included receiving encouragement from family and friends and having a good relationship with your GP. To ensure processing of this focussing information, participants were asked to rate how much they identified with the information they read and how much they could apply it to themselves.

Procedure

Members of the public were approached in community areas including supermarket car parks, cafes and market stalls. Posters were used to advertise the project and interested parties were provided with a leaflet outlining what the study involved and the main aims. The researcher or a member of the research team were available for participants to ask questions and to enquire whether individuals met the eligibility criteria. The research team emphasised that participation in the study was entirely voluntary, and that participants could change their mind at any stage while completing the questionnaires, without giving any reason. It was estimated that participating in the study would take approximately 20 minutes and it was anticipated that all participants would complete the study in situ. On completion of the questionnaire, participants were provided with a £10 gift voucher as a small thank you for their time.

Materials

Two questionnaire packs were designed specifically for the study. Each pack was divided into two parts. Both packs 1 and 2 had an identical part one which contained demographic

¹⁴ <https://www.randomizer.org/>

questions, brief information about OCD (reading), and a brief questionnaire asking participants to rate the likelihood of seeking help if they were to develop OCD on a Likert scale (see appendix 5).

The information contained in the second part of the pack was the experimental arm. Therefore, the control group (pack 1: see appendix 6) and the enablers (pack 2: see appendix 7) were presented with different information. The control group were presented with 'more information about OCD' whilst enablers read information about 'what might help people to seek treatment for their OCD'. The control group were then asked to answer (on the same Likert scale) ten questions aimed at focussing them on the information they just read. In contrast, the enablers were asked to answer a similar set of ten questions encouraging them to focus on the information they had read. After reading the type of information presented, and answering the specified focussing questions, both groups were then asked again to rate the likelihood of seeking help should they develop OCD.

Ethical Considerations

It was decided that debriefing participants about the details of the study after they had completed their questionnaire was not appropriate. Due to the nature of data collection it was felt that should the details of the two arms of the study be shared, the accuracy of the results would be compromised. Additionally, to maintain confidentiality participant contact details were not collected making debriefing at a later date problematic. Consequently, the research team advised participants that they would be able to access the results of the study which would be posted on the University of Bath the Clinical Psychology webpage later in the year. The project was approved by the University of Bath Ethics Committee (reference 14-138).

Participants Treatment of Data

Initially, 133 participants were recruited. Missing data and inappropriate responding (endorsing multiple items) rendered six participants' data unusable reducing the sample to 127. Preliminary analysis revealed that a high proportion of participants rated themselves at the maximum level of the dependent variable, prior to the intervention, meaning that the distribution of scores were not normally distributed and the extent of any the change could not be normally distributed as in those instances a ceiling effect would operate. Therefore, those who scored 90 or above on the initial rating of the fourth question (the anticipated likelihood that they would undertake CBT for OCD) were not included in the final sample to

deal with ceiling effects; in other words, participants who scored 90 or above at baseline can, by definition, only change in one direction. Ratings for the fourth question in particular were excluded as they had the highest overall mean score at baseline (mean of 75.56, SD 24.30). The rationale for exclusion on the basis of ceiling effects was in line with previous documented research (MacInnes, Salkovskis, Wroe and Hope, 2015). This operation subsequently resulted in the exclusion of 52 people. This excluded group did not differ ($p > .1$) from the total sample in terms of gender or age. The final sample included 34 males and 41 females. Of those 33% were between the ages of 26-35 years with 87 % reported as White British and 42% achieving diploma or degree level education. Half of the sample reported being employed full time. Details of sampling and inclusion are reported below in the results section. The final sample reported here was therefore 75 people (39 controls and 36 enablers).

The mean ratings made by the whole sample and the sample included are shown in table 9 for comparison purposes. Additionally, the included vs excluded cases were compared on gender balance using a chi square ($\chi^2 [1, N = 127] = 0.73, p > .05$.) and age using an independent samples t tests (mean included 45.77, SD 15.15; mean excluded 43.32, SD 17.77) $t = 0.82$. The included vs excluded were comparable in terms of these demographics.

Participant Demographic Information

Table 10: Demographic information of the total sample prior to data screening

Demographic Variable	Frequency/Percent	
	Controls: 68 (51.1)	Enablers: 65 (48.9)
Gender		
1. Male	24 (35.3)	32 (49.2)
2. Female	44 (64.7)	32 (49.2)
Age		
1. 19-30	17 (25)	24 (36.9)
2. 31-40	10 (14.7)	11 (16.9)
3. 41-50	9 (13.2)	7 (10.8)
4. 51-60	15 (22.1)	9 (13.8)
5. 61-70	12 (17.7)	11 (16.9)

6. 71 +	5 (7.4)	2 (3.0)
Ethnicity		
1. White British	58 (85.3)	49 (75.4)
2. White other	5 (7.4)	5 (7.7)
3. White Irish	1 (1.5)	8 (12.3)
Education		
1 Left school early	2 (2.9)	1 (1.5)
2. Left school at 16	1 (1.5)	1 (1.5)
3. CSE's/equivalent	4 (5.9)	1 (1.5)
4. GCSE's/equivalent	4 (5.9)	0
5. A	9 (13.2)	4 (6.2)
levels/equivalent	27 (39.7)	28 (43.1)
6. Diploma/degree	20 (29.4)	28 (43.1)
7. Postgraduate		
Employment Status		
1. Unable to work	4 (5.9)	3 (4.6)
2. Unemployed	0	1 (1.5)
3. Student	4 (5.9)	2 (3.1)
4. Employed part-time	14 (20.6)	4 (6.2)
5. Employed full-time	29 (42.6)	43 (66.2)
	13 (19.1)	12 (18.5)
6. Retired	4 (5.9)	0
7. Other		

Table 11: Means and standard deviations for all four variables, pre and post intervention for both groups, before and after data screening

SAMPLE	Variable	Enablers		Controls	
		Pre	Post	Pre	Post
1 (N127)	1. Likelihood of finding out about CBT	71.37 (SD 27.97)	80.48 (SD 20.20)	66.69 (SD 28.32)	74.31 (SD 25.62)
	2. Likelihood of seeing GP	61.13 (SD 29.09)	69.35 (SD 23.18)	58.31 (SD 30.55)	64.15 (SD 30.87)
	3. Likelihood of asking for CBT	67.58 (SD 28.21)	74.03 (SD 23.64)	62.31 (SD 28.22)	67.85 (SD 29.71)
	4. Likelihood of going for CBT	75.56 (SD 24.30)	80.65 (SD 21.41)	73.85 (SD 24.54)	78.31 (SD 22.61)
2 (N75)	1. Likelihood of finding out about CBT	60.83 (SD 27.50)	75.30 (SD 22.23)	56.15 (SD 27.49)	64.62 (SD 25.53)
	2. Likelihood of seeing GP	46.94 (SD 24.00)	61.11 (SD 23.03)	51.03 (SD 29.72)	58.21 (SD 30.68)
	3. Likelihood of asking for CBT	50.00 (SD 23.66)	64.44 (SD 23.72)	53.59 (SD 27.38)	59.49 (SD 28.00)
	4. Likelihood of going for CBT	59.31 (SD 19.20)	70.28 (SD 21.97)	58.72 (SD 20.28)	65.38 (SD 20.50)

Randomisation was checked in terms of age and gender; the enablers and controls were not different in gender balance (40 % controls and 51% enablers male, 60% controls and 49% enablers female) $\chi^2(1, N = 75) = 1.19, p = .28$. Nor were they different in terms of age (mean 3.6 for controls (SD 1.8) and 3.0 enablers (SD 1.8) $t=1.3$).

Data Analytic Strategy

Statistical analysis was carried out using SPSS (IBM, 2013). Independent T-tests were used to test whether the groups differed on the initial ratings and demographic factors such as age and sex. No difference was found with $P>.1$ in all cases.

The decision ratings were first subject to an internal consistency analysis at baseline using Cronbach's alpha. As the internal consistency was good these ratings were regarded as appropriate to consider as a single scale as the primary variable, giving a 2X2X4 mixed model ANOVA, with the key effect of interest being the two-way time X group interaction. The inclusion of the four measures separately allowed identification of potential three way interactions. Thus, pre and post the focussing procedures were the other within subjects' factor, and experimental group (enabler or control) as the grouping factor.

Pearson's product moment correlations were used to identify the relationship between the rating variables use as the experimental procedure (ratings were also checked for internal consistency prior to totalling) and the amount of change in ratings of likelihood of treatment seeking between first and second time of measurement. By definition, this was done separately for the two experimental conditions.

Results

Rating of Likelihood of Seeking Treatment for OCD

An analysis of variance was completed across all four dependent variables. The main effect of time was significant ($f [1,73] = 38.5, p < 0.0001$). The main effect of subscale was also significant ($f [3,71] = 9.0, p < 0.0001$). The main effect of group was not significant ($f [1,73] = 0.33, p > 0.1$). The third order interaction was not significant ($F < 1$). No interactions were observed for subscale by group ($f < 1$) or time by group ($F [1,73] = 1.3, p > 0.01$). However, the crucial pre-post x group interaction was significant ($f [1,73] = 3.8, p = 0.05$). See figure 5 below.

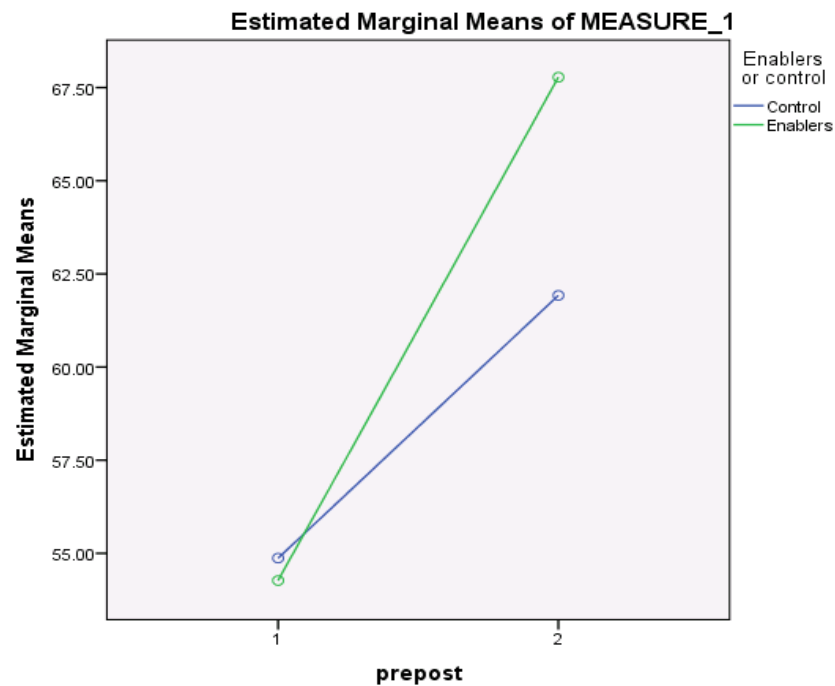


Figure 5: Interaction between pre-post ratings and group

Supplementary analysis: Analysis prior to data screening (including those scoring above 90 on item 4)

As a further supplementary analysis, the data was analysed including those scoring at ceiling levels at baseline. An omnibus repeated measures (2X4X2) ANOVA was completed with the four rating scales and time of assessment as within/repeated measures and experimental group as grouping factor. The top section of table 9 above illustrates the means. The Box test of equality of variance/covariance was significant ($p < 0.0001$) indicating major problems with the distribution. As noted previously, the distributions were bimodal, with a large number of people scoring 100 on all four variables.

The main effect of time was significant ($F [1, 125] = 29.8, p < 0.001$). The main effect of subscale was also significant ($f [3, 125] = 23.1, p < 0.0001$). The main effect of group was not significant ($f [3, 125] = 0.45, p > 0.05$). No second or third order interactions were significant with $p > 0.05$ in all cases. The key subscale by group interaction was also not significant ($p > 0.05$).

Clearly the major deviation from normality limits conclusions from this analysis, and in the absence of interactions further effects were not investigated. Overall it can be tentatively

concluded that both groups showed and increased likelihood of seeking help from the first measurement to the second (Pre mean 67.1 [SE= 2], Post mean 73.6 [SE= 1.9]).

Extent of change in rated likelihood of seeking treatment (pre and post intervention)

In order to explore whether the extent to which participants felt that focussing information applied to them, affected their likelihood of seeking treatment, an analysis of the change scores (pre-to post) was conducted. Analysis of the means of the four DV ratings; mean change for controls was 7.0 (SD 12.4) and for enablers was 13.5 (16.1), $t(73) = 1.95$, $p = 0.05$, indicating a larger change in the enabler group relative to controls.

The final stage of the planned analysis involved calculating the total amount of change following making the ratings (before to after) and the total of the ratings made in each of the two experimental conditions (for the four dependent variables). That is, the extent to which each participant considered the factors rated applied to them¹⁵. Total ratings and change scores were correlated for each group meaning that significance of 0.025 or less was required on the basis of a Bonferroni Correction. The ratings provided by controls did not correlate with change in likelihood of seeking help ($r = -0.08$, $p > 0.5$) whereas ratings made by enablers correlated highly and significantly with change in likelihood of seeking help ($r = 0.663$, $p < 0.0001$). A scatterplot was created in order to ensure that the distributions were representative of a bivariate normal distribution. See figure 6 below.

¹⁵ Justification for the use of total ratings comes from an analysis yielded a high internal consistency for both conditions (control alpha of 0.83, enablers' alpha of 0.9).

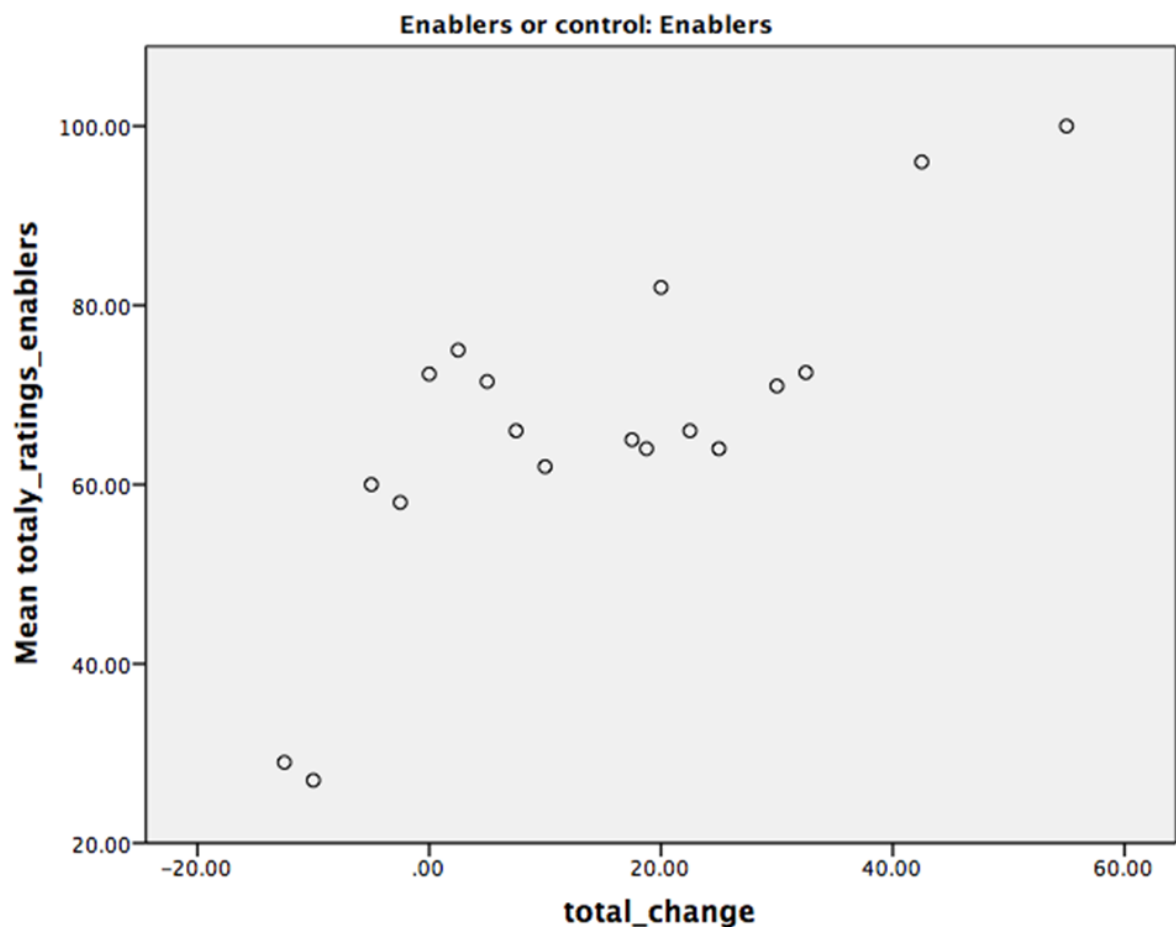


Figure 6: The correlation between the total change scores and total rating scores generated by enablers.

From this we can conclude that the higher the ratings for enablers, the greater the change observed. That is, the extent to which enablers felt that the focussing ratings applied to them, influenced the extent of shift in their scores. Given that a similar relationship between focussing ratings and extent of shift was not observed in the control group, it can be assumed that there was something about focussing on enabling factors that encouraged people to think about seeking treatment in a particular way.

Discussion

The current research sought to establish whether the type of information presented to and focussed on by community controls (without OCD) would influence the likelihood that they would seek treatment if they developed OCD. Specifically, it was hypothesised that focusing participants on the factors which encourage people to seek help (enablers) would increase their rated likelihood of seeking help for OCD. Secondly, it was expected that focusing participants on more detailed general information about OCD this would not significantly increase hypothetical help-seeking behaviour. It was proposed that this process would work by systematically drawing attention to and promoting the procedure of already known enabling factors.

Findings from the current study only partially supported this hypothesis as both groups of participants' hypothetical help seeking responses increased post intervention. In regards to the secondary hypothesis it was found that the increase in ratings of likelihood of seeking treatment was greatest in those focussing on enablers. The finding of a correlation between total change scores and total rating scores in enablers suggests that only in that condition were the issues which were focussed on having a specific effect, over and above what could be a non-specific effect. That is, just thinking about OCD may increase the likelihood of seeking help, but thinking about enablers may do so more powerfully. In other words, the extent to which participants thought focussing items applied to them impacted on the extent of change observed in their ratings.

It is possible that both types of information given and focussed on had an effect on outcome responses. If we consider that a lack of information about OCD has been widely documented as a barrier to seeking treatment (Nestad, Samuels, Romanoski, Folstein, and McHugh, 1994; Fireman, Koran, Leventhal and Jacobson, 2001; Goodwin, Koenen, Hellman, Guardino, and Struening, 2002; Stengler-Wenzke and Angermeyer, 2005; Torres *et al.*, 2006; Belloch *et al.*, 2009; García-Soriano, Rufer, Delsignore and Weidt, 2014; Robinson, Rose and Salkovskis, in press) , then it stands to reason that providing any type of clarifying information to participants would have an effect on treatment seeking behaviour. Therefore, it can be presumed that providing people with any type of information may be beneficial, but that focussing on enabling factors is more facilitative in terms of adjusting people's attitudes towards treatment seeking.

Whilst these findings are not as strong as previous research (Wroe, Salkovskis and Rimes, 1998; Wroe and Salkovskis, 2000; Wroe, Salkovskis and Rimes, 2000; Salkovskis, Rimes,

Bolton and Wroe, 2010), this could be explained by the methodological differences between studies, specifically, the absence of focussing on barriers (negative focussing) or focussing per se (i.e. on OCD irrelevant information). Additionally, the current intervention combined the type of information presented with a focussing task, which is an alteration from previous research. It is noteworthy therefore that differentiating between which aspect of the experimental condition made the most difference to the likelihood of seeking treatment is it is problematic.

Furthermore, the decision being made here was hypothetical, therefore caution is needed in drawing any conclusions about help seeking behaviour. Consistent qualitative feedback received from participants during testing was that they found it challenging to imagine themselves developing OCD like symptoms. Existing evidence has highlighted the strong correlation between hypothetical and actual treatment seeking behaviour (Salkovskis *et al.*, 2010). However, previous research has usually explored the likelihood of people seeking pre-emptive testing for a particular health or mental health condition. Contrastingly, the current study pertained specifically to the likelihood of seeking treatment for OCD, not testing. This may be an important differentiating and extraneous variable to consider when comparing the current findings to the literature base. It is also possibly that the hypothetical nature of the current study was too abstract for people to make an accurate judgement of whether or not they would seek help for OCD.

Findings are consistent with the literature demonstrating that decision outcomes correspond with areas in which people are encouraged to focus on at the time of decision making (Wroe and Salkovskis, 2000; Wroe, Salkovskis and Rimes, 2000; Salkovskis, Rimes, Bolton and Wroe, 2010). In the current study it was inferred that providing people with information that focuses on the factors which encourage people to seek help, significantly increase their rated likelihood of seeking help were they to develop OCD. It is recommended that if the research were to be repeated, sampling a larger more diverse population would be beneficial to establish whether the observed effect can be generalised. Further research should also focus on providing neutral and negative enablers in addition to positive ones to explore whether a difference exists in likelihood of seeking help with different types of information. Moreover, more research is needed to establish whether a difference exists between written and oral dissemination of information, and whether hypothetical help seeking ratings correspond to actual uptake of treatment for OCD. Results from the current research have important implications for clinical practice. It is possible that providing enabling information at the

earliest possible time may allow people to access appropriate treatment sooner, potentially and influencing the long term impact of OCD symptoms.

Limitations and implications for future research

Some further limitations of the study need to be highlighted. The current participant population was heavily weighted in terms of demographics, which it was assumed was a reflection of the geographical location of sampling. It is possible that this may have had a bearing on the results. Additionally, it is possible that the ceiling effect observed in the rating scales could be a by-product of a learning bias, or indeed a consequence of social desirability factors. Although it was felt that excluding participants that demonstrated a ceiling effect was appropriate for the current analysis (and supported by previous research) it is important to note that this significantly reduced the sample size. In an effort to counteract this limitation, the research team are continuing data collection, implementing a pre-screening process to eliminate outliers prior to intervention.

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Executive Summary/Dissemination Document for Main Research Paper

Title: Seeking help for OCD – A Community Focusing Study

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Candidate: Sarah Elliott

Hand-in-date: 25th July 2016

Clinical Tutor: Lorna Hogg

Background

Despite the fact that OCD is a treatable condition, sufferers often delay many years before seeking treatment (Pinto, Mancebo, Eisen, Pagano, and Rasmussen, 2006; Stobie, Taylor, Quigley, Ewing, and Salkovskis, 2007; Belloch, Del Valle, Morillo, Carrio, and Cabedo, 2009). This delay can and usually does have significant direct and indirect costs for the individual. Over time OCD symptoms can become chronic having a profound impact on individual's psychosocial functioning and quality of life (Hollander *et al.*, 1996; García-Soriano *et al.*, 2014). It has been widely acknowledged that a lack of information about OCD can act as a significant barrier to treatment seeking (Robinson, Rose and Salkovskis, in press). Existing research from the physical health arena suggests that the type of information presented to individuals during the decision making process can influence whether or not they choose to seek treatment. In particular, it has been reported that decision outcomes correspond with the areas in which individuals are encouraged to focus at the time of decision making (Wroe and Salkovskis, 2000; Wroe, Salkovskis and Rimes, 2000; Salkovskis, Rimes, Bolton and Wroe, 2010). Conversely, the psychological processes involved in the decision to seek treatment for OCD have received surprisingly little research attention. This is especially important due to the fact that OCD is an example of a mental health problem where delays in presentation for diagnosis and treatment are the rule rather than the exception. In order to establish whether similar mechanisms operate for decisions around psychological treatment seeking, an analogue study was conducted with members of the public who do not have OCD.

Method

The present study included 75 community volunteers (without OCD) who were asked to complete a questionnaire about whether they would seek treatment for OCD, should they develop symptoms. Participants were randomly assigned to one of two groups. Group 1 (the control group) were asked to read some general information about OCD, whilst Group 2 (the enablers) were asked to read information about 'what might help people to seek treatment for their OCD'. To ensure processing of this focussing information, participants were asked to rate how much they identified with the information they read and how much they could apply it to themselves. Ratings of whether or not people were likely to seek treatment for OCD were taken before and after the intervention to monitor any adjustments in hypothetical help seeking behaviour.

Results and Conclusions

Findings from the current study indicated that focussing on enabling factors (that encouraged people to seek treatment) had a significant influence on the likelihood that people would seek treatment for OCD. Furthermore, results demonstrated that both groups of participants' hypothetical help seeking responses increased post intervention. It is possible that both focussing conditions had an effect on outcome responses. Therefore, it can be presumed that providing people with any type of information may be beneficial, but that focussing on enabling factors is more facilitative in terms of adjusting people's attitudes towards treatment seeking.

Implications for Research

- The current research was based on a small sample size and therefore the generalisability of the findings are limited. It is advised that the research should be repeated with a larger population to establish whether the effect is valid with a larger group.
- The demographic group recruited in the current sample was quite restrictive and appeared limited in cultural, socioeconomic and educational background. It is recommended that the current research be replicated with a wider demographic to assess whether the findings can be generalised.
- More research is needed that includes negative as well as positive enablers for treatment seeking in OCD.
- The current study adopted a neutral control group which included 'more information on OCD'. However, the overall findings indicated that providing any type of information could influence an individual's likelihood of seeking treatment. Therefore, it would be important to repeat the current research with the inclusion of a pure control group which asked people to focus on novel or irrelevant data.
- More research is needed to establish whether a difference exists between written and oral dissemination of information.
- Future research may wish to focus on establishing whether hypothetical help seeking ratings correspond to actual uptake of treatment for OCD.

Implications for Clinical Practice

- Results of the current research indicate that providing people with information about OCD is helpful for promoting help seeking behaviour. In particular, information that focusses on enabling factors was noted as having the biggest influence on decision making outcomes for treatment. Should this finding be replicated in other research, it would be important to highlight the relationship between information provided and treatment seeking. Specifically, to GP's who are the gatekeepers for mental health services. Providing the right information at the earliest possible time may subsequently enable people to access appropriate treatment sooner. This would potentially have a profound impact on OCD sufferers making the condition less debilitating and reducing the long term effects of symptoms.

Connecting Narrative

Word Count:	974
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Hand-in-date:	25 th July 2016
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The current narrative connects the three research components (literature review, service improvement project and main research project) and five clinical case studies. Firstly, some general overarching themes of the work are considered with emphasis placed upon identifying links between the three projects. Then each research project shall be discussed individually in relation to the rationale for topic selection, research process, ethical considerations, any alterations to plans and impact on practice. Finally, the trainee's personal reflections about the process will be highlighted and any impact these have on future clinical and research plans outlined.

Themes and Observations

Reflecting on academic, clinical and research elements of my clinical training, two major themes emerged. Firstly, there is a clear theme of the treatment of complex co-morbid mental health difficulties in the context of challenging life circumstances. This signifies a developing clinical and academic interest for me in how to work with individuals within these parameters, the role of complex formulation and transdiagnostic, and idiosyncratic treatment approaches. This was particularly poignant throughout the clinical case studies and allowed me develop skills in complex formulation which was beneficial in my elective placement in Secure Forensic Services. Secondly, much of the focus of the work included here involves an element of adjustment and acceptance of psychological distress. Again this theme developed as a key clinical interest of mine and sparked my selection of elective placements.

Critical Literature Review

The main focus of my critical review was to explore the phenomenology of sexually intrusive thoughts in sex offenders and compare findings with existing research from clinical and non-clinical populations. My personal interest in this topic developed from a clinical and ethical dilemma faced by one of my placement supervisors. A case arose of a woman with OCD who experienced sexually intrusive thoughts. The extent of the lady's reassurance seeking meant that clinicians were finding it difficult to assess whether the woman had acted on these thoughts. This placed her care team in a difficult situation as her living accommodation viewed her as a risk and began taking steps to restrict her movement illegally. Reflecting on the teaching given, I became curious as to how different interpretations of risk and consequent management effected individuals' experiences and I developed an interest in understanding this phenomenon from different perspectives. The challenge with the review was the amalgamation of forensic and clinical literature. Differences in terminology used

made this comparison difficult. Conversations were had with experts in both fields in an effort to explore this issue, all of whom reinforced the value of the work. It is therefore hoped that this review has been able to highlight gaps in current understanding and suggest directions and methodologies for future research that may address these.

Contributions to the Project

The review was designed, developed, and undertaken with advice and supervision from Professor Paul Salkovskis (Academic Supervisor). Furthermore, advice and guidance was received from Dr Christine Purdon, Dr Bill Marshall and Dr Madeline Lockmuller.

Service Improvement Project (SIP)

The main focus for the SIP was to identify the physical and psychological needs of relatives in ITU. Furthermore, it was hoped that information generated from the project would highlight areas in which relatives' needs were currently being met, and provide guidance as to how this can be improved to more effectively reflect the ethos of family-centred care. Motivation for the completion of this project came from personal experience of having a relative admitted to ITU. Discussions with field supervisor Dr Mike Osborn highlighted that exploration of the needs of relatives in critical care services at the Royal United Hospital would be beneficial. Similarly, the project felt timely given the ongoing service developments taking place at the RUH. It was hoped that findings from the project would help shape future services to provide better support to relatives within critical care.

Contributions to the Project

Development of the project was completed by myself and Dr Mike Osborn (field supervisor). Advice, practical support and supervision was provided by Dr Catherine Butler (Academic Supervisor). Clinicians working in the service assisted by promoting the research to potential relatives. In particular, recruitment was assisted significantly by specialist nurse Debbie White.

Main Research Project

I have always had an interest in working within Deaf services having been trained in Makaton language programme through previous employment. Conducting research in this area was inspired by teaching delivered by Dr Mary Griggs on working with Deaf service users. Dr Griggs also became a consultant on the project, helping to shape ideas and understand the specialist literature.

It had been widely documented that caring for a Deaf child or a child with other additional needs can be a stressful experience. However, little research has attempted to examine the relationship between the child's co-morbid difficulties and impact on caregivers. This lack of evidence therefore provided the researchers with significant opportunities to offer original contributions to the field. Significant difficulties were experienced in the obtainment of ethical approval for the study. It was understood that some of the challenges experienced were reflective of the realities of conducting research in Deaf services. It was anticipated that

In an effort to minimise the impact of this, Dr Maria Gascon-Ramos was brought on board as a field supervisor. Dr Ramos had extensive experience conducting research in Deaf services and was the service manager of the Taunton NDCAMHS site utilised. Dr Ramos

Unfortunately, Dr Ramos went off on maternity leave during the research process and did not return during the research schedule. Resultantly, Jenny Kent (acting service manager) consulted on the project in Dr Ramos's absence.

However, being able to highlight the need for evidence in this area was a meaningful and motivational factor in driving completion of the study. Additionally, the research was a multi-site design which meant that the researcher was exposed to inconsistencies in Research and Development requirements that delayed the approval process.

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Clinical tutors: Andrew Medley and Lorna Hogg

Research and Project collaborators: Christine Purdon, Bill Marshall, Mary Griggs, Maria Gascon-Ramos, Jenny Kent, Mike Osborn, Debbie White and Claire Damen.

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In addition, I would like to thank the entire course team and visiting lecturers, and all of my placement colleagues who helped me throughout this experience. To all of the service users who have been so honest and open with me during difficult times, you have taught me so much, thank you.

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Thank you all.

Appendices

Appendix One:

Summary table of the empirical papers used in the review

Authors	Focus	Sample	Method	Validity comments
1. Banse, Schmist and Clarbourn (2010)	Indirect measures of sexual interest of sex offenders	Total sample 113 (all Caucasian). N=38 sex offenders and N= 75 non offending controls All male.	Self-report questionnaire: 1. The Explicit Sexual Interest Questionnaire 2. Four different viewing time measures regarding sexual interest in men, women, girls, and boys were used 3. Balanced Inventory of Desirable Responding	Small sample of sex offenders compared to controls. Lack of balanced sample within sex offender groups and lack of balanced proportion of homosexual men in the control sample.
2. Belloch, Morillo, Lucero, Cabedo and Carrio (2004)	Frequency of appearance of intrusive thoughts in normal population	Total sample 336 non clinical population, N= 203 female and N= 133 male.	Self-report questionnaire: 1. Obsessional Intrusions Inventory– Revised Initial standardised interview to probe for the presence of mental disorders, medical conditions and psychological or pharmacological treatments.	The recruitment of subjects was carried out using as a basis a series of seminars for final year Psychology students that were trained in the purpose of the study.
3. Blumenthal Gudjonsson and Burns (1999)	Cognitive distortions and blame attribution in sex offenders against adults and children.	2 groups of sex offenders. Separated on the basis of the age of their victims. a) N= 36 child sex offenders b) N=30 adult sex offenders All male.	Compared on measures of cognitive distortions relating to sex with children and rape and a measure of blame attribution which assesses external, mental element, and guilt feeling attributions. Self-reported questionnaire: 1. MOLEST scale 2. RAPE scale 3. Revised Gudjonsson blame attribution inventory 4. Other deception and self-deception questionnaire	Psychologist and prison officers selected participants for inclusion. Inconsistency in data collection method - Some participates data collected in groups and some individually.
4. Byers, Purdon and Clark (1998)	Examined sexually intrusive thoughts in a non-clinical	171 college students undertaking psychology	Self-report Questionnaire: 1. Revised Obsessional Intrusions	Participants received bonus credit towards course grade.

	population	course. (113 female, 58 male)	Inventory – Sex Version (ROI-v2) 2. The sexual opinion survey 3. The sexual daydreaming scale (SDS) 4. The obsessive thoughts checklist 5. The positive emotionality scale (PEM)	
5. Cathey and Wetterneck (2013)	Stigma and disclosure of intrusive thoughts about sexual themes	University students sample N= 157 Participants (18-60 years). N= 120 female, 37 male.	Adapted vignette questionnaire to measure participant reaction to a hypothetical disclosure of an intrusive thought	Psychology students from one university and given extra credit for participation. Based on vignettes, limited external validity. Unweighted sample in terms of gender.
6. Clark, Purdon and Byers (2000)	Appraisal and control of sexual and non-sexual intrusive thoughts in university students	171 university students undertaking psychology course (N=113 female, N=58 male)	Self-report questionnaires: 1. Revised Obsessive Intrusions Inventory-sex Version (self-report measure) 2. Sexual opinion survey (SOS) 3. Obsessive thoughts checklist (OTC)	Participants received bonus points towards course grade. Same sample as earlier study.
7. Giambra and Martin (1977)	Sexual Daydreams and Quantitative Aspects of Sexual Activity: Some Relations for Males Across Adulthood	277 adult males 24 -91 years of age. Selected from the Baltimore Longitudinal Study of the Gerontology Research Centre.	Self-report questionnaires: 1. The Imaginal Processes inventory 2. Structured interview of sexual life history	Large and diverse sample The reliability of self-report data collected at interview potential limitation as can't be corroborated.
8. Hanson, Gizzarelli and Scott (1994)	The Attitudes of Incest Offenders Sexual Entitlement and Acceptance of Sex with Children	50 male incest offenders were compared with those of 25 male batterers and 25 men not seeking treatment	Developed the Hanson Sex Attitudes Questionnaire. Contained subscales that addressed sexual entitlement, the perception of children as sexually attractive and sexually motivated, and minimizing the harm caused to children by sexual abuse.	Found that incest offenders perceived children as both sexually attractive and sexually motivated, and they minimise the harm caused by sexual abuse. Development of new questionnaire measure.

9. Hanson and Harris (2000)	Dynamic predictors of sexual assault recidivism	Sexual offenders recruited from the correctional system. 208 offence recidivists and 201 non-recidivists. Non-recidivist were selected from community sample who had not reoffended within 15 months.	Interviews with community supervision officers and file reviews using: 1. Statistical information on recidivism 2. Hare psychopathy checklist 3. Violence risk appraisal guide 4. Rapid risk assessment for sexual offense recidivism	Sample was matched in terms of offense histories, victim type and jurisdiction. Participants matched on variety of salient factors, details not extensively provided.
10. Heckert and Gondolf (2000)	Predictors of Underreporting of Male Violence	840 men who were admitted to batterer programmes across 4 cities. The first 20–25 men appearing for program intake each month were recruited into the sample.	Developed prediction equations of underreporting. 1. the Conflict Tactics Scale, using a multi-site database search. Analysing: a) Reports of the incident that led to programme referral from men's, women's, and police reports (b) men's and women's reports of re-assaults collected during a 12-month program follow-up.	Content and length of programmes attended varied. Strategic sampling method, no randomisation.
11. Howells and Wright (1978)	Compared sexual attitudes of samples of sexual and non-sexual offenders. Investigated personality, intellectual and social background correlates of sexual attitudes.	Sample recruited from English 'special hospitals'. N=34 sex offenders N= 23 non sex offenders (i.e. males admitted to the hospital for non-sexual offences).	Measures given: 1. The Sex Inventory 2. Welsh's anxiety scale 3. Extraversion 4. Sociability 5. Impulsivity	Both groups were tested on admission to hospital.
12. Hudson, Ward and McCormack (1999)	Offense Pathways in Sexual Offenders	86 incarcerated sexual offenders recruited from medium security units in New Zealand.	Examined offence pathways of offenders through analysis of offence transcripts. Descriptions of offending history were assisted by therapists and	Analysis was done in line with the model of offence chain.

			transcribed.	
13. Kafka (1997)	Hypersexual Desire in Males: An Operational Definition and Clinical Implications for Males with Paraphilias and Paraphilia-Related Disorders	100 outpatient males: 1. N=65 with paraphilias 2. N=35 paraphilia-related disorders. No random allocation.	The longitudinal history and temporal stability of total sexual outlet were assessed using: 1. Intake Questionnaire and Sexual Inventories	Study subjects were obtained through advertisement, or self-, therapist-, or forensic referral.
14. Kingston and Bradford (2013).	Hypersexuality and Recidivism among Sexual Offenders	586 adult male sexual offenders assessed between 1982 and 1996 at a university affiliated forensic Sexual Behaviours Clinic.	Longitudinal investigation to examine the rate of an objective, behavioral indicator of hypersexuality (Total Sexual Outlet) and to determine the predictive utility of Total Sexual Outlet utilizing one of the longest follow-up periods used with sexual offenders (up to 20 years). 1. The Sex Offender Risk Appraisal Guide 2. Recidivism data obtained from the Canadian Police Information Centre (CPIC)	Sexual outlet measured via number of orgasms achieved during a specific week.
15. Langstrom and Hanson (2006)	High rates of sexual behaviour in the general population: correlates and predictors	2450, 18–60-year-old men and women from a 1996 national survey of sexuality and health in Sweden (1279 men and 1171 women)	Non-clinical sample. Participants contacted via post by health institution. 469 excluded for not meeting criteria. 59% response rate recorded. No gender/sociodemographic differences noted between responders and non-responders. All respondents over age 60 were eliminated to minimize the effects of age-related attrition.	Interviews and questionnaires measured various sexual behaviours, developmental risk factors, behavioural problems, and health indicators.
16. Lykins, Cantor, Kuban, Blak, Dickey, Klassen and Blanchard (2010)	Sexual arousal of gynephillic men to female children.	N= 214 Men selected from referrals made to Kurt Freund Laboratory (Canada) for problematic sexual	1. Retrospective analysis of sexual history using a standardized form. 2. Volumetric Plethysmography testing including a base test and stimuli test. Limitation of sensitivity of physiological	No measure the frequency of sexually explicit material use; thus, a direct relationship between exposure to erotic materials

		behaviours.	responses/measured arousal.	and sexual arousal patterns cannot be made.
17. Marshall, Marshall, Moudlen and Serran (2008)	The Prevalence of Sexual Addiction in Incarcerated Sexual Offenders and Matched Community Non-offenders	Total sample n= 231 males. Consisted of N= 114 incarcerated sex offenders and N=117 non offender community adults	Self-reported questionnaire: 1. Sexual Addiction Screening Test (SAST)	Community non- offenders paid for participation.
18. Morillo Belloch, Garcia-Soriano (2007)	Clinical obsessions in OCD patients and obsession-relevant intrusive thought in non-clinical, depressed and anxious subjects	Recruited from attendees to outpatient mental health clinics. OCD N=31, Depression N= 22, Anxiety disorder N= 25, Plus Non clinical community subjects N= 30	Self-reported questionnaires, 1. Obsessional Intrusions Inventory-Revised 2. Yale–Brown Obsessive–Compulsive Severity Scale 3. Padua Inventory-Washington State University Revision 4. Maudsley Obsessive–Compulsive Inventory 5. Beck Depression Inventory 6. Automatic Thoughts Questionnaire 7. Automatic Thoughts Questionnaire 8. State-Trait Anxiety Inventory-State	Examined the frequency, contents, emotional impact, consequences, cognitive appraisals and control strategies associated with clinical obsessions in OCD patients compared with 3 control groups.
19. Müller, Curry ,Ranger, Briken, Bradford and Fedoroff (2014)	Changes in Sexual Arousal as Measured by Penile Plethysmography in Men with Paedophilic Sexual Interest	N= 43 men diagnosed with paedophilia collected from a sexual behaviour clinic.	Penile tumescence (PPT) (as a proxy for sexual interest) measured by penile plethysmography testing	Retrospective study of PPT results, limitation of physiological measurements
20. O'Connor, Aardema, Bouthillier, Fournier, Guay, Robillard, et al. (2005)	Evaluated an inference-based approach (IBA) to the treatment of OCD by comparing its efficacy with a treatment based on the cognitive appraisal model	44 participants completed the 20-week therapy. Randomly allocated to CAM, ERP or IBA. a) IBA group N=16	Measures used: 1. Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) 2. The Padua Inventory 3. The Cognitive Intrusions Questionnaire (CIQ)	Small sample size. Lack of preselection of people with high and low Primary inferences meant there were not equal numbers in each condition.

	(CAM) and exposure and response prevention (ERP).	b) CAM group N=16 c) ERP group N=12	4. The Beck Anxiety Inventory 5. The Beck Depression Inventory 6. The Obsessive Beliefs Questionnaire	
21. Purdon and Clark (1994)	Obsessive intrusive thoughts in nonclinical subjects: Cognitive appraisal, emotional response and thought control strategies	270 Students enrolled in an introductory psychology class. Participants received course credit for their participation.	Self-report questionnaires 1. Padua Inventory 2. Obsessional Intrusions Inventory	Original sample of 293 was reduced to 270 as some participants didn't complete the full questionnaire due to time constraints.
22. Rachman, Hodgson and Marks (1971)	The treatment of chronic obsessive-compulsive neurosis	10 patients with chronic obsessive-compulsive neurosis	Longitudinal study. Comparison of two treatments – Flooding vs Modelling.	Small sample size, lack of standardisation.
23. Radomsky <i>et al.</i> (2014)	Intrusive thoughts in university students across six continents	N= 777 University students	Interviews and self-report questionnaires: 1. International Intrusive Thoughts Interview Schedule Version 6 (IITIS) <ul style="list-style-type: none"> • IITIS sections A–C: interview information, demographics, medication and psychiatric history. • IITIS section D: definition and example of an unwanted intrusive thought • IITIS sections E–J: UIT content areas • IITIS section L: most distressing UIT • IITIS section M: appraisals of the MD-UIT • IITIS section N: control strategies used for the MD-UIT • IITIS section O: failures of control 	University students only, however comprehensive interview and outcomes measures.

			<ul style="list-style-type: none"> • IITIS section P: interviewer comments 2. Obsessive-Compulsive Inventory – Revised 3. Obsessional Beliefs Questionnaire 4. Depression Anxiety Stress Scale – Short Version	
24. Renaud and Byers (1999)	Exploring the frequency, diversity and content of university students' positive and negative sexual cognitions	N= 292, 148 female and 144 male heterosexual undergraduate students	Self-report questionnaire: 1. 56-item positive and negative sexual cognition check list 2. measures of sexual adjustment (i.e. sexual experience, sexual functioning) 3. measures of daydreaming, and social desirability	University students only
25. Rowa, Purdon, Summerfeldt and Antony (2005)	Why certain obsessional thoughts are more upsetting than others for people with obsessive compulsive disorder	N=28 (71% female) participants with a principal diagnosis of OCD. Participants were recruited from among patients presenting to a specialty anxiety disorders clinic.	Self-reported questionnaire 1. Yale–Brown Obsessive Compulsive Scale 2. Positive and Negative Affect Schedule and 3. Interpretation of Intrusions Inventory 4. Attribute Listing 5. Current Concerns Interview	Questionnaires and interviews completed at two different periods of time on (1) their most upsetting current obsession and (2) their least upsetting current obsession
26. Salkovskis and Warwick (1986)	Morbid preoccupations, health anxiety and reassurance: a cognitive-behavioural approach to hypochondriasis	N=2 two cases of health anxiety, both males	Case study of cognitive based therapy approach	Case studies only therefore limited external validity.
27. Scott and Tetreault (1987)	Attitudes of Rapists and Other Violent Offenders Toward Women	Total N= 60 consisting of: Prison inmates: N=20 incarcerated rapists, N=20 non sex-related	Self-report questionnaire 1. Attitude toward women scale (AWS)	Study completed by external researchers (not authors).

		violent offenders and N=20 matched subjects in a control group. Drawn from vocational training programme.		
28. Simonds and Thorpe (2003)	Attitudes toward obsessive-compulsive Disorders	N=113, first-year undergraduate psychology students participated as part of course requirements N= 86 female and N=27 male	Responses to vignettes – 1. Described a person with extensive washing compulsions 2. Vignette described a person with checking obsessions and compulsions. 3. Described a person with doubting, violent (related to killing parents/harming self) and blasphemous obsessions and related compulsions. Each vignette was followed by 19 questions that required participants to evaluate the vignette.	Homogeneous sample – university students only. Students required to participate.
29. Smith and Waterman (2004)	Processing Bias for Sexual Material: The Emotional Stroop and Sexual Offenders	N= 10 sex offenders, N=10 violent offenders, N=10 non-violent offenders and N=13 undergraduate students	Self-report questionnaires: 1. State-Trait Anxiety Inventory 2. Social Desirability Scale 3. Beck Depression Inventory 4. The Aggression Questionnaire, BPAQ 5. Barratt Impulsivity Scale	Small sample, all participants were Caucasian
30. Templeman and Stinnet (1991)	Patterns of sexual arousal and history in a sample of young men	N= 60 Undergraduate male students.	Self-report questionnaire 1. Clarke Sexual History Questionnaire 2. Farrenkopf Arousal Portfolio and Cardsort 3. Additional questions related to potential previous offending	Homogeneous sample – university students only. Given college credit for participation
31. Thornton (2002)	Constructing and Testing a Framework for Dynamic Risk	N= 158 incarcerated adult male paedophiles	Retrospective analysis of criminal history of offenders across 3 domains –	Retrospective analysis of prison records.

	Assessment		1. Distorted Attitudes 2. Socio-affective Functioning, 3. Self-Management	
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Appendix 2: Copy of Information sheet, demographic information and consent form

Royal United Hospital Bath 
NHS Trust



Identifying and Addressing the Needs of Relatives in Critical Care Services at the Royal United Hospital

Information Sheet

We understand that having a relative admitted to the intensive care unit can be a daunting and stressful experience. We would like to do all that we can as a service to ease the pressure placed on family members of ITU patients. In order to do this, we want to gather the views of relatives currently attending ITU and establish what we are currently doing that helps support families during this difficult time, and also what we can do to improve this service to help reduce the stress caused by the process.

The project will be conducted by Sarah Elliott; a trainee clinical psychologist based at the University of Bath, and will be supervised by Dr Mike Osborn, Consultant Clinical Psychologist based here at the RUH. The project has obtained ethical approval from the Psychology Research Ethics Committee at the University of Bath, in addition to the Research and Development Department of the RUH and will be conducted in line with the British Psychological Societies code of ethics and conduct for research (2009).

What does participation involve?

Participating in this project will involve completing a questionnaire detailing what you need physically, socially and psychologically to help support you while your relative is in the ITU. These could range from available facilities, the quality and type of care provided to communication with staff and information sharing. The questionnaire should take no more than 20 minutes of your time to complete. Results from all of the questionnaires will be collated and analysed to help identify current areas of strength as well as areas in which we can improve. You will also be asked to complete some background questions about your relative's admission to ITU, (for example, how long they have been there). This information will help us to better understand the background of your experience. Should you not wish to complete this section of the questionnaire then please feel free to leave it blank. Please answer the questions as honestly as you can.

The data collected will not contain any personal information about yourself or your relative (except the background information you have chosen to provide). Once you have completed your questionnaire, please place it in the designated post box in the ITU waiting room (if you have used any additional sheets of paper please attach these to your questionnaire before posting). This ensures that your information is kept confidential and keeps your participation in the project separate to other services you may be receiving from the department.

Participation in the project is entirely voluntary and you may stop being a part of the study at any time without explanation. You have the right to ask that any data you have supplied up to that point be withdrawn or destroyed. Choosing to take part/not take part in the study will

have no implication for your relatives' treatment here at the ITU. We simply wish to gather your opinions on how we currently meet your needs as a relative, and how we can work hard to improve this experience for you.

What will happen to the findings from the project?

After the project is completed, we would like to invite you to attend a service user feedback group. The aim of this group is to discuss the main issues arising from the project and outline how we plan to address these practically within the ITU department to improve relatives' experiences. This also gives us an opportunity to hear what you think about how to improve the service and also to share your experiences with the project team. The feedback group will be held at the RUH and relatives who have opted into this stage will receive a letter from the facilitator outlining the details of the session at a later date. If you wish to take part in the service user feedback group then please detach and complete the consent form at the rear of this information pack, providing the facilitator with your contact details. Consent forms should also be posted in the designated post box located in the ITU waiting room.

Results from the current project will be analysed and published in a clinical report that will be provided to the Royal United Hospital Bath NHS Trust, and the ITU staff team. If it is deemed appropriate the report will be summarised and a copy left in the ITU waiting room for the benefit of other relatives. Should you wish to receive a summary of the project findings through the post, please indicate this on the consent form at the back of the pack. All data collected (from questionnaires and focus groups) will remain anonymised and summarised for the purposes of this report only. In the unlikely event that taking part in this study has a negative effect on you, a debriefing meeting shall be offered by the project team, and signposting to relevant services may be appropriate.

FOR FURTHER INFORMATION

Sarah Elliott (facilitator) will be glad to answer any questions about this study at any time. You may contact her at:

Sarah Elliott

S.Elliott@bath.ac.uk

Clinical Psychologist in Training

Doctorate in Clinical Psychology

University of Bath

BA2 7AY

You may also email the project team with any questions or concerns you may have about the project.

Dr Mike Osborn: mike.osborn@nhs.net

Dr Catherine Butler: c.a.butler@bath.ac.uk

Thank you very much for your time

**“Identifying and addressing the needs of relatives in Critical
Care Services at the Royal United Hospital”**

Statement of Consent

Thank you for considering participating in the current project. By signing below, you are agreeing that:
(1) you have read and understood the Information Sheet, (2) questions about your participation in this
study have been answered satisfactorily, (3) you are aware of the potential risks (if any), and (4) you
are taking part in this study voluntarily (without coercion).

Participant's Name (Printed)*

Participant's signature*

Date

To help us place your needs into context, it would be really helpful if you could answer the following questions as honestly as you can.

How old is your relative? _____

What is your relationship to the person currently receiving care in the ITU? _____

Was your relatives' admission to ITU: Planned ☐ Unplanned ☐

How many days have they spent in ITU to date: _____

Have they ever been admitted to the ITU before? Yes ☐ No ☐

Approximately, how far do you live from the hospital?

Less than a mile ☐ Up to 5 miles ☐ Up to 10 miles ☐ Over 10 miles ☐

Appendix 3: Copy of the adapted Critical Care and Family Need Inventory (CCFNI) used for the study

To help us provide you with the best service, we would like to understand how important each of the following needs is to you currently as a relative of an ITU patient. Please tick only one answer for each need.

Today's date: _____

Need	Not important	Slightly important	Important	Very important
1 To feel that there is hope				
2 To feel that hospital personnel care about the patient				
3 To have the waiting room near the patient				
4 To be called at home about changes in the condition of the patient				
5 To know the prognosis				
6 To have questions answered honestly				
7 To know specific facts concerning the patients progress				
8 To receive information about the patient once a day				
9 To have explanations given in terms that are understandable				
10 To see the patient frequently				
11 To feel accepted by hospital staff				
12 To have a bathroom near the waiting room				
13 To be assured that the best care possible is being given				
14 To know why things were done for the patient				
15 To know exactly what is being done for the patient				
16 To have comfortable furniture in the waiting room				
17 To know how the patient is being treated medically				
18 To have friends nearby for support				

	Need	Not important	Slightly important	Important	Very important
19	To be told about transfer plans while they are being made				
20	To be assured it is alright to leave the hospital for a while				
21	To visit at any time				
22	To have a telephone near the waiting room				
23	To have explanations of the environment before entering ITU				
24	To have good food available in the hospital				
25	To have the pastor visit				
26	To talk to the doctor daily				
27	To have visiting hours start on time				
28	To talk about the possibility of the patient's death				
29	To help with the patients physical care				
30	To have directions as to what to do at the bedside				
31	To know what staff members could give what type of information				
32	To talk to the same nurse each day				
33	To know about the types of staff members taking care of the patient				
34	To have a specific person to call at the hospital when unable to visit				
35	To be told about chaplain services				
36	To be told about other people who could help with problems				
37	To have someone be concerned with the relatives health				
38	To have a place to be alone while in the hospital				
39	To be alone at any time				

	Need	Not important	Slightly important	Important	Very important
40	To be told about someone to help with family problems				
41	To be encouraged to cry				
42	To have another person with the relative when visiting ITU				
43	To have visiting hours changed for special conditions				
44	To have someone to help with financial problems				
45	To talk about negative feelings such as guilt or anger.				

To help us identify areas in which we can improve our service to best support relatives in ITU, please use the scale below to let us know how well the ITU currently meets the needs you have identified as ***“most important”*** overleaf. Please write which need you are referring to and tick the box that best represents how you feel that need is currently being met. Please be as honest as possible. Should you require additional space, please utilise one of the spare question sheets provided and include it in with your completed questionnaire.

1. Need identified: _____

Not at all	Partially	Satisfactory	Quite Well	Very Well

2. Need identified: _____

Not at all	Partially	Satisfactory	Quite Well	Very Well

3. Need identified: _____

Not at all	Partially	Satisfactory	Quite Well	Very Well

4. Need identified: _____

Not at all	Partially	Satisfactory	Quite Well	Very Well

5. Need identified: _____

Not at all	Partially	Satisfactory	Quite Well	Very Well

(3) Please outline any further suggestions you think would be helpful in the box below:

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Appendix 4: The Frequency, percentage and ranking of questions identified by relatives as “most important” by theme.

Frequency (4)	Ranking	%	Need	Theme
24	1	100%	To have questions answered honestly	Assurance
23	2	96%	To feel that hospital personnel care about the patient	Assurance
22	3	92%	To know the prognosis	Assurance
22	4	92%	To have explanations given that are understandable	Assurance
22	5	92%	To be assured that the best care possible is being given to patient	Assurance
21	6	88%	To be called at home about changes in the patient's condition	Proximity
20	7	83%	To know why things were done for the patient	Information
19	8	79%	To know how the patient is being treated medically	Information
19	9	79%	To have visiting hours changed for special conditions	Proximity
17	10	71%	To know specific facts concerning the patient's progress	Assurance
17	11	71%	To talk to the Dr everyday	Information
16	12	67%	To feel there is hope	Assurance
16	13	67%	To see patient frequently	Proximity
16	14	67%	To have a bathroom near the waiting room	Comfort
16	15	67%	To know exactly what is being done for the patient	Information
16	16	67%	To have visiting hours start on time	Proximity
15	17	63%	To receive information about the patient once a day	Proximity
15	18	63%	To feel accepted by the hospital staff	Comfort
15	19	63%	To be told about transfer plans while they are being made	Proximity
14	20	58%	To help with the patient's physical care	Information

Frequency (4)	Ranking	%	Need	Theme
14	21	58%	To have someone be concerned with the relative's health	Support
13	22	54%	To have the waiting room near the patient	Proximity
13	23	54%	To visit anytime	Proximity
13	24	54%	To talk about the possibility of the patient's death	Support
12	26	50%	To be assured it is all right to leave the hospital for a while	Comfort
12	27	50%	To have a telephone near the waiting room	Comfort
12	28	50%	To have directions as to what to do at the bedside	Support
12	29	50%	To know which staff members could give what type of information	Information
12	30	50%	To have a place to be alone while in the hospital	Support
11	31	46%	To have friends nearby for support	Support
11	32	46%	To have explanations of the environment before going into the critical care unit for the first time	Support
11	33	46%	To have someone to help with financial problems	Support
10	34	42%	To have good food available in the hospital	Comfort
9	35	38%	To be told about someone to help with family problems	Support
9	36	38%	To talk about negative feelings such as guilt and anger	Support
8	37	33%	To be told about other people that could help with problems	Support
8	38	33%	To be alone at any time	Support
5	39	21%	To talk to same nurse daily	Proximity
5	40	21%	To have a specific person to call at the hospital when unable to visit	Information
5	41	21%	To be encouraged to cry	Support
4	42	17%	To know about the types of staff members taking care of the patient	Information
4	43	17%	To have another person with the relative when visiting the critical care unit	Support
3	44	13%	To have the pastor visit	Support

2	45	8%	To be told about chaplain services	Support
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Could we ask you a favour?

We are hoping that 80 members of the public who do not have obsessive compulsive disorder (OCD) might be able to help us.

Could you spare 20 minutes to help us with a research study?

In appreciation we are able to offer you a voucher as a small thank you.

Researchers: Sarah Elliott & Paul Salkovskis

University of Bath Research Ethics Committee Ref: 14-138

Could we ask you a favour?

Are you a member of the public who does not have obsessive compulsive disorder (OCD)?

Could you spare 20 minutes to help us with a research study?

What is the research about?

You may know that obsessive compulsive disorder (OCD) is an anxiety disorder which can interfere hugely in people's lives. We are doing a programme of research on the topic of 'Seeking help and receiving appropriate treatment for OCD'. This is one of the research studies in the programme.

People with OCD often delay seeking help, and we are trying to learn more about this, so that we can hopefully encourage people to seek help earlier. We would like to learn more about which sort of information is most useful to people e.g. it might be that is more helpful to focus on some types of information than others.

What would it involve?

In this study we are hoping that **80 members of the public who do not have OCD** might be willing to take part in a short study. The study would involve:

- * having a brief chat with one of the researchers so that she could answer any questions you might have, and signing a Consent Form
- * reading two short pieces of information about OCD and seeking help, and completing short questionnaires before and afterwards

The study is completely voluntary and takes about **20 minutes** in total. Your Consent Form would be separated from your questionnaires to ensure confidentiality.

The first piece of information you would read will be the same for everybody. The second piece will vary: some people will read one kind of information, others will read a different kind. We have ideas about which kind of information might be the most useful but we don't know. If you decided you'd like to take part in the study, the second piece of information you would read would be decided at random.

On completion of the study you would receive a voucher as a small thank you for your time.

Interested in the results of the study?

The results of the study will be published on our website some time in 2016. You would be most welcome to have a look at them. In the write-up we will describe the two different types of information we were comparing in this study.

www.bath.ac.uk/psychology/postgraduate/clinical/

Your wellbeing while participating in the study

This project has been reviewed and approved by a University of Bath Research Ethics Committee (Ref: 14-138). Applying for ethical approval involved thinking about any possible negative effects the study could have on members of the public taking part.

We anticipate that the overall effect of taking part would be positive or neutral for you. However, if after taking part in the study, you felt you would like to talk about any topics arising from the study you would be most welcome to contact one of the researchers, Sarah Elliott, at S.Elliott@bath.ac.uk and she would be very happy to arrange to ring you back.

If you felt troubled in any way after taking part in the study our colleague, Paul Salkovskis, would also be available to speak on the phone. His number is: 01225 385506 or he can be contacted at: P.M.Salkovskis@bath.ac.uk

Thank you for reading this!

Researcher

Sarah Elliott:

S.Elliott@bath.ac.uk

Postal address: Sarah Elliott, Clinical Psychologist in Training, Department of Clinical Psychology, 10 West, 3.41, University of Bath, Claverton Down, Bath. BA2 7AY.

CONSENT FORM



We would be very grateful if you could complete this form after you have read the Information Sheet and / or listened to an explanation about the research.

Title of Research Project: **Seeking help for obsessive compulsive disorder (OCD)**

Names of Researchers: Sarah Elliott

University of Bath Research Ethics Committee Ref: 14-138

Please initial box

- | | | |
|----|--|--------------------------|
| 1. | I confirm that I have read and understand the Information Sheet dated 25/05/16 (version 2) for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. | I understand that my participation is voluntary and that I am free to change my mind while completing the study, without needing to give any reason. | <input type="checkbox"/> |
| 3. | I understand that my Consent Form will be separated from my questionnaires to ensure confidentiality. I consent to information from my questionnaires being published in the final report (it will not be possible to identify me from the publication). | <input type="checkbox"/> |
| 4. | I agree to take part in the above project. | <input type="checkbox"/> |

Name of Participant	Date	Signature
.....

Name of Researcher taking consent	Date	Signature
.....

You would be very welcome to have a copy of this Consent Form if you would like one.

Initial questions about yourself

Participant Number

1. Age2. Female / Male3. Ethnic Origin

Please circle the heading which best describes your ethnic origin:

Bangladeshi	Other Black	White British
Indian	Chinese	White Irish
Pakistani	Mixed – White & Asian	White Other
Other Asian	Mixed – White & Black African	Any Other
Black African	Mixed – White & Black Caribbean	Prefer not to say
Black Caribbean	Other Mixed	

4. Education

Please circle the highest level of education that you have completed:

School not completed	'A' Levels or equivalent
School not completed due to health reasons (please state)	Diploma or degree
Left school at 16, but did not sit / pass exams	Postgraduate qualification
CSEs or equivalent	Other (please describe briefly)
GCSEs or equivalent	

5. Employed / Retired etc

Are you currently (please circle one):

Not able to work e.g. on incapacity benefit	Employed (full-time)
Unemployed – available for work	On sick leave (from work)

If unemployed, could you say how many years since last employment?	
Student	Retired
Employed (part-time)	Other (please describe briefly e.g. carer, homemaker)

People you have known

Have you known any people with a mental illness personally?

Yes ☐ No ☐

If yes, how many people with a mental illness have you known personally?

Up to 3 people	4 – 6 people	7 – 9 people	10 – 12 people	13 – 15 people	Over 15 people
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Have you known any people with obsessive compulsive disorder (OCD) personally?

Yes ☐ No ☐

If yes, how many people with OCD have you known personally?

Up to 3 people	4 – 6 people	7 – 9 people	10 – 12 people	13 – 15 people	Over 15 people
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We would be very grateful if you could read the following information about obsessive compulsive disorder (OCD):

Obsessive compulsive disorder (OCD)

Obsessive compulsive disorder (OCD) is generally thought of as an anxiety-related problem.

People with OCD experience obsessions and compulsions.

Obsessions often involve intrusive thoughts about fear of causing harm. Examples might be:

"Could I have run somebody over?"

"Did I turn the gas off?"

"Could I ever abuse a child?"

Examples of compulsions might be:

- * washing your hands, cleaning excessively or avoiding using public toilets
- * banishing knives or avoiding children altogether
- * trying to think a good thought to cancel out a bad thought

In the short-term these compulsions usually reduce the anxiety by making people feel safer, but they can make it worse. In the longer-term however they always make the problem worse.

OCD is diagnosed if the obsessions and compulsions are distressing to the person, take a significant amount of time, and if they are stopping the person doing things which are important to them. For some people the problem is completely disabling.

The good news is that effective treatments now exist for OCD; a psychological therapy called cognitive behavioural therapy (CBT), and medication.

Cognitive behavioural therapy (CBT) works by helping people to interpret their intrusive thoughts in a different way, and helping them not to carry out compulsions. This includes learning that their fears do not mean they are a danger to anyone and that their fears are exaggerations of natural worries.

People can completely recover from OCD. Unfortunately however it is very common for people to delay seeking treatment. The average age OCD starts is 20. On average the delay between someone developing OCD and seeking help is 11 years. This means that OCD damages many very important years of a person's life.

There are many reasons for this delay, which can include; feeling embarrassed, not wanting to have a mental health record, or not knowing there is treatment available.

People may eventually be driven to seek help because they are worn out by their OCD or because they have reached a crisis point.

People with OCD have also described a number of more positive factors which helped them seek treatment. These include knowing that the problem is OCD, trusting their GP and feeling confident that their GP / mental health professionals would be able to help, and family or friends encouraging them to seek help. They also described feeling confident that the right treatment would help them deal with their OCD, and feeling that this treatment would enable them to do the things they really wanted to do in life.

As OCD is a recognised condition, and it can be treated, no-one should have to struggle with it.

In this section we would ask you to imagine that **you have developed symptoms of OCD yourself.**

Imagining this, please could you answer the following questions. Under each question please circle the number which best represents your answer.

Imagine that **you have developed symptoms of OCD yourself:**

How likely is it that you would find out more about cognitive behavioural therapy (CBT)?
(the recommended psychological treatment for OCD)

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

How likely is it that you would see your GP to discuss your OCD and the possibility of treatment?

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

How likely is it that you would ask to have cognitive behavioural therapy (CBT) for your OCD?

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

If you were offered a course of at least 12 sessions of cognitive behavioural therapy (CBT) for your OCD, how likely is it that you would go for it?

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Appendix 6: Part two of the focussing intervention for Controls

We would be very grateful if you could now read the following information:

More information about obsessive compulsive disorder (OCD)

It is estimated that 1% of people in the U.K. have obsessive compulsive disorder (OCD).

Lets have a more detailed look at obsessions. Obsessions are thoughts, ideas, images, impulses or doubts which pop into people's heads, and are unwanted.

People with OCD become very anxious about their obsessional thoughts and are unable to ignore them. Obsessions tend to focus on things which are very important to the person e.g. harm coming to others.

The obsessional thoughts trigger compulsions where people feel that they must try to prevent the things they fear from happening, or undo things they fear they have already done.

Compulsions can be actions you can see such as washing or checking, or they can be inside someone's head such as going over things in your mind to check them, or cancelling them out with a particular thought or image.

In the short-term these compulsions usually reduce the anxiety by making people feel safer, but they can make it worse. In the longer-term however they always make the problem worse.

There are usually obvious connections between people's obsessive fears and their compulsions, e.g. people who fear contamination often wash, people who fear harming people often check.

The good news is that effective treatments now exist for OCD; a psychological therapy called cognitive behavioural therapy (CBT), and medication.

Cognitive behavioural therapy (CBT) works by helping people to interpret their intrusive thoughts in a different way, and helping them not to carry out compulsions.

People can completely recover from OCD.

In this section we would ask you to imagine again that **you have developed symptoms of OCD yourself.**

Imagining this, please could you rate how much the following statements apply to you:

Imagine that **you have developed symptoms of OCD yourself:**

If I had OCD, obsessions such as thoughts, ideas, images, impulses or doubts would pop into my head.

Does not apply at all Applies very much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

If I had OCD my obsessions would be unwanted.

Does not apply at all Applies very much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

If I had OCD I would become very anxious.

Does not apply at all Applies very much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

If I had OCD I would not be able to ignore the intrusive thoughts.

Does not apply at all Applies very much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

If I had OCD my obsessions would tend to focus on things which are very important to me.

Does not apply at all Applies very much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Continuing to imagine that **you have developed symptoms of OCD yourself:**

If I had OCD my obsessional thoughts would trigger compulsions.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

If I had OCD I would feel that I must try to prevent the things I fear from happening.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

If I had OCD, carrying out compulsions would usually help me feel less anxious in the short-term.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

If I had OCD, carrying out compulsions would always make the problem worse in the longer-term.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

If I had OCD there would usually be an obvious connection between my obsessive fears and my compulsions.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Continuing to imagine that **you have developed symptoms of OCD yourself.**

please could you answer the following questions on this final page.

Under each question please circle the number which best represents your answer.

Imagine that **you have developed symptoms of OCD yourself:**

How likely is it that you would find out more about cognitive behavioural therapy (CBT)?
(the recommended psychological treatment for OCD)

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

How likely is it that you would see your GP to discuss your OCD and the possibility of treatment?

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

How likely is it that you would ask to have cognitive behavioural therapy (CBT) for your OCD?

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

If you were offered a course of at least 12 sessions of cognitive behavioural therapy (CBT) for your OCD, how likely is it that you would go for it?

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Thank you very much for your time.

Appendix 7: Part two of the focussing intervention for Enablers

We would be very grateful if you could read the following:

What might help people to seek treatment for their obsessive compulsive disorder (OCD)?

The good news is that effective treatments now exist for OCD; a psychological therapy called cognitive behavioural therapy (CBT), and medication.

Cognitive behavioural therapy (CBT) works by helping people to interpret their intrusive thoughts in a different way, and helping them not to carry out compulsions.

People can completely recover from OCD. Unfortunately however it is very common for people to delay seeking treatment. The average age OCD starts is 20. On average the delay between someone developing OCD and seeking help is 11 years. This means that OCD damages many very important years of a person's life.

People with OCD have described a number of factors which have encouraged them or pushed them to seek help. These include;

- * learning that it is a recognised anxiety problem called OCD
- * learning that their fears do not mean they are a danger to anyone – that their fears are exaggerations of natural worries
- * learning that there is effective treatment for OCD
- * friends or family encouraging and supporting them in seeking help
- * feeling completely worn out by their OCD
- * reaching a crisis point because of their OCD
- * people whose obsessional fears are about causing harm may feel driven to seek help to prevent that harm
- * having a good and trusting relationship with their GP
- * feeling confident that their GP / mental health professionals would be able to help
- * feeling confident that the right treatment would help them deal with their OCD
- * feeling that getting treatment would enable them to do the things they really want to do

In this section we would ask you to imagine again that **you have developed symptoms of OCD yourself.**

Imagining this, please could you rate how much the following statements apply to you:

Imagine that **you have developed symptoms of OCD yourself:**

Learning that it is a recognised anxiety problem called OCD would help me seek treatment.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Learning that my fears do not mean I am a danger to anyone would help me seek treatment.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Learning that there is effective treatment would help me to seek treatment.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

My family / friends would encourage me and support me in seeking help.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Feeling completely worn out by my OCD would push me to seek help.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Continuing to imagine that **you have developed symptoms of OCD yourself:**

My obsessional fears about causing harm may drive me to seek help to prevent that harm.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Having a good and trusting relationship with my GP would help me to seek treatment.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

I would feel confident that my GP / mental health professionals would be able to help.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

I would feel confident that the right treatment would help me deal with my OCD.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Getting treatment would enable me to do the things I really want to do.

Does not
apply at all

Applies very
much

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Continuing to imagine that **you have developed symptoms of OCD yourself.**

please could you answer the following questions on this final page.

Under each question please circle the number which best represents your answer.

Imagine that **you have developed symptoms of OCD yourself:**

**How likely is it that you would find out more about cognitive behavioural therapy (CBT)?
(the recommended psychological treatment for OCD)**

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

How likely is it that you would see your GP to discuss your OCD and the possibility of treatment?

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

How likely is it that you would ask to have cognitive behavioural therapy (CBT) for your OCD?

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

If you were offered a course of at least 12 sessions of cognitive behavioural therapy (CBT) for your OCD, how likely is it that you would go for it

Not at all

Definitely

0.....10.....20.....30.....40.....50.....60.....70.....80.....90.....100

Thank you very much for your time.